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ABSTRACT

The handbook provides parents of children with disabilities guidance on planning for the child's future needs with special attention to resources and laws of Iowa. Section 1 gives a Future Planning Checklist and definitions of common legal terms. Section 2 addresses estates, trusts, and wills and provides common estate planning questions and answers, a family estate planning inventory, and a sample of a simple will. Section 3 covers guardianship and conservatorship including new Iowa legislation. Section 4 examines health care coverage and financing and includes: the major types of health care coverage; recommended pediatric benefits; Medicaid and Medicare; Iowa Comprehensive Health Association; Association for Retarded Citizens insurance programs; the Early and Periodic Screening, Diagnosis and Treatment Program; and a glossary of health insurance terms. Considered in section 5 are residential and community based services such as residential and intermediate care facilities, group foster care, respite care, the Family Support Subsidy Program, and camps. Supplemental income is examined next including Supplemental Security Income and Medicaid, federal payments and redetermination, and change of status. Tax information is given in section 7 and additional information, such as sources of free or low cost help in Iowa, in section 8. Includes 50 resources and references. (DB)

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PLANNING FOR THE FUTURE OF YOUR CHILD WITH A DISABILITY

Second Edition

Enhancing the Parent-Educator Connection Project
Iowa Department of Education, Bureau of Special Education
and Drake University
January 1990

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INTRODUCTION

The original document Planning For The Future Of Your Child With A Disability was developed by the Parent Educator Connection Project, Iowa Department of Education, Bureau of Special Education and Drake University. It was a compilation of information accompanied by pamphlets and resource material from governmental agencies and public and private organizations. This publication is an update of the original document and materials and is published in a format that allows ease in duplication of the entire document or separate sections. All sections have been revised to reflect changes in, as well as the addition of, current services and guidelines. Materials that did not lend themselves to easy duplication, but were found to be of benefit are included in the References and Resource Section with a brief abstract of the material. It is recommended that after going through each major section individuals review the resource and reference listing and, if interested, contact the agency, organization or publisher for a copy of the referenced material. If there is a known cost for the resource or reference material, it is listed.

It is our hope and intent that parents and professionals will find some of the information and suggestions helpful as they begin to pian for the future of children with disabilities. It is not the purpose nor intent of this document to render any legal advice but to offer general information in areas of concern when planning for your child's future. It is recommended that one consult an experienced attorney regarding all legal matters such as estate planning, wills, trusts, taxes, etc. Additionally, this publication does not address all of the areas or concerns that will be encountered as one begins to face and plan for the future. If there are ways to improve this resource document that will be of benefit to you or others, please let us know.

We hope you find this information helpful.

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Section One

PLANNING FOR THE FUTURE

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PLANNING FOR THE FUTURE NEEDS OF A CHILD WITH DISABILITIES

Future planning for most families is a difficult and time consuming task. Difficult because of all the factors that need to be considered and because it requires time to search for information, decide what to do, and then carry out with planned steps and activities. Future planning for the care of a child with a disability can seem even more complex because of considerations for long term care and services that generally go beyond considerations for children and young adults who do not have a disability. However complex and time consuming it may seem at the start, it is not an impossible task nor beyond the means of every parent regardless of their experience or financial situation.

Planning for the future of your child with a disability is on-going. Laws, regulations and services continually change. Needed services, support and/or benefits that are not in existence today may very well be in place a year from now. Advice from professionals such as attorneys, case managers and care givers are critical to the process of future planning. However, the final decisions and preparations for a comprehensive long range plan is the sole responsibility of the parent. It is the parent who best understands the needs of their child and it remains the parent who must take the initiative to ensure the appropriateness of any future plan. Some of the decisions you will have to make will be difficult; some you may not want to face. However difficult or overwhelming they may seem at the time, it is important to remember that those difficult decisions and seemingly overwhelming tasks are not impossible. Remember, you are not alone. Many parents just like you are facing the same decisions and many have encountered the same frustrations. Talk to other parents as well as the professionals. Share your concerns and don't be afraid to seek advice and ask questions. The struggle will be worth it because you will know that you have done the best you could to help make your child's future secure.

For most families, there are several areas to consider when planning for the future of their daughter or son who has a disability. Some of these are:

HOUSING. Where will my child live? If that option is no longer available, what is the alternative? Who will make the decision as to where my child will live?

SOCIAL/LEISURE/RECREATIONAL NEEDS. In what future events do I want my child to participate?

RELIGIOUS. Do I want my child to observe religious holidays and attend services? If so, which ones and what denomination? When my child dies, what kind of service do I want him/her to have? Where should he/she be buried?

HEALTH CARE. What kind of checkups do I want my child to have? How often? Does my child have any health care needs that I am currently aware of that need to be planned for?

EMPLOYMENT. What are my employment goals for my child?

CAREER/VOCATIONAL OR ACADEMIC TRAINING. What do I expect my child to know and be able to do? What do I want my child to participate in? For how long?

TRANSPORTATION NEEDS. What will the transportation needs be for my child? Who or what will provide transportation?

LEGAL SERVICES. Will my child ever have a need for legal services? Who should provide them? What legal services should be considered?

FINANCIAL. How will all of the needs mentioned above be paid for? Who will make the decisions about payment?

GUARDIANSHIP. Do I want to appoint a guardian? Who? If he/she isn't available, who would be an alternate or who should appoint an alternate? What should the guardian be responsible for? Is he/she a guardian of the person, the estate or both?

Also consider what local, state and federal programs your child is eligible for. Some to explore are:

SUPPLEMENTAL SECURITY INCOME (SSI)
MEDICAID
SOCIAL SECURITY BENEFITS
MEDICARE
FOOD STAMPS
VETERANS BENEFITS

Some of these are explained in more detail in other sections of this document.

A FUTURE PLANNING CHECKLIST

Below is a checklist which may help parents begin to plan for their child's future. Parents can review the checklist and identify items that are important to them and their child. Take time when going through the checklist. If after reading a question on the checklist, you are uncertain about the answer, mark it "NO". The questions that you mark "NO" are the ones where you will want to focus your time and energy. Remember, fudging on the answers won't help anyone - least of all your child.

I. GENERAL INFORMATION

Yes___ No___ Do you have copies of your current will?

Yes___ No___ Do you have the birth dates and current addresses of your children?

Yes___ No___ If divorced, do you have copies of the divorce decree and property settlement agreements?

Yes___ No___ Are you certain of your handicapped child's current legal status, (do you have copies of guardianship orders, etc.)?

Yes___ No___ Have you prepared a list of your tangible property (autos, furnishings, etc.) and their values?

Yes___ No___ Do you have totals of your current savings and checking accounts? Do you have the account numbers?

Yes___ No___ Do you have deeds to all of your real property (home, vacation home, rental property, land, etc.)?

Yes___ No___ Do you have copies of your stock and bond certificates?

Yes___ No___ Do you have copies of your insurance policies?

Yes___ No___ Do you have up-to-date information on any pension plans you have?

Yes___ No___ Have you prepared a list of your existing liabilities (mortgage, auto payments, other indebtedness)?

Yes___ No___ Do you have a list of assets which may be in the name of your child who is handicapped?

Yes___ No___ Do you have a list of the governmental benefits and assistance which your child currently receives?

Yes___ No___ Does your child have a Social Security Number? (If not, get one for him/her).

II. INFORMATION REGARDING YOUR WILL

Yes___ No___ Do you have a legal last will and testament?

Yes___ No___ Have you identified someone to serve as a Executor of your estate? Have you discussed their role in regards to your child?

Yes___ No___ Have you determined what portions of your estate are to be left to whom?

Yes___ No___ Have you drafted a Letter Of Intent, regarding in what manner your child is to be cared for after your death?

Yes___ No___ Have you drafted a Letter Of Last Instructions which discusses funeral arrangements, location of important documents, etc.?

Yes___ No___ Do the individuals who will be responsible for implementing provisions have a copy of your will and last testament?

Yes___ No___ Have you specified that the assets left to your child with a disability are to be used to supplement and NOT supplant his/her support and care, thus jeopardizing eligibility for government entitlements and benefits?

III. INFORMATION PERTAINING TO YOUR HANDICAPPED CHILD'S PERSONAL PROTECTION

Yes___ No___ If your child is a minor, have you considered the appropriateness of provisions for his/her guardianship after he/she reaches age 18?

Yes___ No___ If appropriate, have you selected a person to act as an advocate or advisor for your child who is handicapped? Have you discussed this with the person selected?

Yes___ No___ If appropriate, have you selected a person to serve as guardian for your child who is handicapped? Have you discussed this with the proposed guardian?

Yes___ No___ Have you selected alternates to serve for each of the persons mentioned above, in the event they are unable to serve when the time comes? Have you discussed this with the alternates?

Yes___ No___ Have you considered naming an advisor to the above-named personal protectors? Have you discussed this with the proposed advisor?

IV. INFORMATION PERTAINING TO YOUR CHILD'S FINANCIAL PROTECTION

Yes___ No___ Have you determined whether to leave property directly to your child or to a third-party?

Yes___ No___ If appropriate, have you identified an informal financial manager to handle assets on behalf of the child? Have you discussed this with the person?

Yes___ No___ If appropriate, have you selected an individual or corporation to serve as a conservator for the child? Have you discussed this with the proposed conservator?

Yes___ No___ Have you considered naming alternates for those above, in the event that they are unable to serve when the time comes? Have you discussed this with the alternates?

Yes___ No___ Have you considered naming an advisor to the above named financial protectors? Have you discussed this with this person?

V. INFORMATION PERTAINING TO FUTURE PLANNING DOCUMENTS

Yes___ No___ Have you determined a secure storage place for the originals of your will and the related documents mentioned?

Yes___ No___ Have you distributed a sufficient number of copies of all important documents to the appropriate persons?

Yes___ No___ Do you have in writing all information regarding the child's characteristics, behaviors, likes and dislikes, etc., so that protectors and others will be knowledgeable about him/her?

Note: Revised from: A Future Planning Guide For Parents of Developmentally Disabled Persons. The Guardianship, Advocacy & Protective Services Board of the Association For Retarded Citizens of Oregon. Reprinted by permission.

DEFINITIONS OF COMMON LEGAL TERMS

Administration of Estates: The management and settlement of an estate of a deceased or incompetent person.

Administrator: A person appointed by a probate court to administer an estate.

Adult: One who has reached the age of majority and full legal responsibility, as defined in Iowa Code.

Age of Majority: The age at which an individual is recognized as an adult. In Iowa it is 18.

Assets: Money or property which an individual owns or possesses.

Attorney at Law: A person who is formally licensed to give legal advice and try cases in court. In the United States the term "attorney at law" is synonymous with lawyer, counselor at law, and barrister.

Beneficiary: One for whose benefit a trust is created, or the person to whom a policy of insurance is payable.

Bequest: A gift of personal property in a will; technically the word "devise" means a gift of real property in a will, but "bequest" is often used synonymously with devise.

Capacity: The legal ability to sue or be sued based on a person's presumed ability to exercise his or her rights. For example, minors lack capacity to bring lawsuits on their own behalf. A guardian ad litem may be appointed by a court to represent a person lacking legal capacity to sue or be sued. Capacity also refers to legal or actual ability to make other kinds of decisions.

Co-Executor: A person named with one or more persons or corporations in a will to perform the duties of execution of the terms of the will.

Community Property: Generally the property acquired by either a husband or wife during their marriage. Community property is only recognized in eight states.

Contribution: The reimbursement of a person who has paid a debt or judgment of others who are also responsible for its payment.

Dependent: A person who must depend on another for support.

Discretionary Powers: Powers that provide a trustee many options in managing a trust's assets and in adapting the benefits furnished to the beneficiary in order to accommodate varying situations.

Disinherit: To prevent an heir from obtaining possession of one's property after death.

Distribution: In probate this is the apportioning of property according to the will, estate plan or intestate succession.

Domicile: A person's permanent residence.

Emancipation: The independence of a minor from parental control and custody, when such independence gives the minor the legal status of an adult.

Estate: (1) The property in which a live person has rights or interests; (2) the property left by a deceased or a bankrupt person.

Execution: (1) The fulfilling of any and all legal requirements necessary to make a legal document valid; (2) the enforcement of a legislative or judicial decree or judgment.

Executor (m.) or Executrix (f.): A person who is appointed by a testator to execute the terms and provisions of the testator's will.

Fiduciary: A person who handles another's money or property in a way which involves confidence and trust.

Gift: The transfer of property from one person to another without any contract or consideration.

Guardian: The person who is legally responsible for the care of another person (and/or his or her property) who is incompetent to act for himself. There are many types of guardians (sometimes also called conservators).

Guardian Ad Litem: The person appointed by a court to represent a person lacking capacity ("incompetent") in litigation.

Heir: One who inherits or is entitled by law to inherit the property of another.

Incompetent: A person unable to manage his/her own affairs and discharge his/her responsibilities.

Individual Who Is Handicapped: According to federal law, specifically the nondiscrimination provisions of the Rehabilitation Act of 1973, a "handicapped individual" is "any person who (a) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (b) has a record of such impairment, or (c) is regarded as having such an impairment."

Intestate: Dying without a will.

Joint Tenancy: Property owned by two or more persons, all of whom have the right to automatically succeed to the ownership interest of a joint tenant who dies.

Law: A rule of conduct decreed by a judicial tribunal or a formal enactment by a legislative or executive body.

Letter of Intent: Specifies in your will the manner in which your child is to be cared for after your death.

Life Estate: The right of a person to use property for the duration of his life or for the duration of another's life.

Living Trust: An inter-vivos trust; a trust created during the lifetime of the person creating the trust.

Luxuries Trust: A trust that supplements rather than replaces government aid.

Mandatory Provisions: Statements contained in a trust that require the trustee to act in certain ways.

Morally Obligated Gift: A gift or bequest given to someone with a request that the gift be used only for the benefit of a third party.

Net: The gross amount of assets, recovery or income, less expenses.

Personal Property: Everything other than real property, including houses, cars, jewelry, clothing

Power of Attorney: A written document which gives one the authority to act as another's agent. The power of attorney may be general, in which case the agent can act in all respects for the principal; or special, in which case the agent can only act in limited circumstances for the principal.

Probate: (1) The judicial process which proves a will and oversees its execution; (2) the court which oversees the administration of the estates of persons who are legally incompetent--minors, incompetents, and the dead.

Real Property: Land and whatever is affixed to it.

Remainderman: The person(s) who receives the remaining assets of a trust at the trust's termination.

Settlor: A person who establishes a trust.

Spendthrift Trust: A trust which provides for an irresponsible beneficiary to prevent creditors from garnishing any of the trust. A trust which contains language that specifically instructs the trustee to use the trust benefits to furnish goods and services over and above those supplied by governmental benefits.

Testamentary: Pertaining to a will or an act which plans for the orderly passing of property at one's death.

Testator: (m.) or Testatrix (f.): A person who makes a will.

Trust: A written arrangement which legally gives resources of one person to another person for the benefit of the third person. The holding, managing, protecting, and disbursing of property by one person (trustee) for the benefit of another person (beneficiary). The person who creates the trust is called the trustor or a settlor.

Trust Instrument: The document that creates a trust.

Trustee: A person who owns and manages a trust for a beneficiary.

Undue Influence: That amount of improper influence which overpowers the will of another and induces him to act according to the wishes of the person who is exercising the undue influence.

Valid: Legally binding.

Ward: A person who is the subject of a guardianship.

Will: The written legal declaration of a person's wishes as to the disposition of his property after death.

Note: From Estate Planning for Families with Developmentally Disabled Children, Iowa Developmental Disabilities Council, 1980. Reprinted by permission; and Legal Terms & Definitions, a handout distributed at a workshop session on Future Planning by Robin Cunconan, Legal Advocate, Iowa Protection & Advocacy.

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ESTATE PLANNING

I have a child with a disability who is unlikely to be fully idependent as an adult.

- What will happen to my child when I die?
- How can I make sure he/she will be properly cared for?
- What do I need to consider?
- Who can help me in estate planning?

These are questions that parents of individuals who are disabled ask as they begin to think how they can best provide for their child after their deaths. There is no one right answer to any of the above questions. Just as individuals with a disability are unique, families and family circumstances are unique.

There are several potential problems or concerns parents face as they contemplate and plan how their resources, property and estate is to be divided:

1) the capacity of the son or daughter to manage the property and/or resources

2) property and/or resources are assets and thus may jeopardize eligibility for certain government benefits

3) depending on the value and amount of the assets and/or resources, the individual with a disability may be subject to charges for services and care

4) designation of a guardian or conservator that will provide for the needed care, comfort, support and services and yet allow the son/daughter opportunities for freedom of decision making, independence and managing their own affairs.

Attempts have been made to address the above questions, potential problems and concerns in this section on Estate Planning. The information provided is introductory and for awareness. After becoming familiar with the options available in estate planning, it is recommended that parents consult with their attorney as well as a trust officer in their financial institution. It may also be of benefit to share with those individuals the information contained in this section.

ESTATE PLANNING QUESTIONS MOST OFTEN ASKED BY PARENTS OF CHILDREN WITH DISABILITIES

By Attorney James G. Schilling
Dubuque, Iowa

QUESTION #1 Do I have to disinherit my child with a disability in order to keep his or her share from going to the government?

Absolutely not! There are currently acceptable estate planning rules whereby your child with a disability can participate in the benefits of your estate. You should certainly familiarize yourself with these tools before making a decision to disinherit your child who has a disability.

QUESTION #2 How can I be reasonably certain that the share which I leave to my child who has a disability will be appropriately expended, will be available throughout the child's lifetime, and will not make my child ineligible to receive governmental financial assistance?

In order to answer these questions, you must be familiar with the concept of a trust which is an estate planning tool by which one person has the authority to manage and invest the funds of another. There are only three parties to a Trust arrangement - the Trustor (sometimes also referred to as the Settlor), the Trustee and the Beneficiary. The Trustor is the person with the assets who by agreement sets up the Trust. The Trustee is the person who receives the funds from the Trustor, invests them and has the obligation of seeing to it that the terms of the Trust are carried out. The Beneficiary, of course, is the third party for whom the entire Trust arrangement is created and for whom the benefits are intended.

If the Trust is created or takes effect during your lifetime, it is referred to as a "Living Trust". It is most often created by a written agreement between the Trustor and the Trustee whereby the Trustee agrees to accept the terms of the Trust arrangement and administer it accordingly.

A trust arrangement may also be created in your Will in which case it is referred to as a Testamentary Trust. In this situation, the Trust is not created nor does it begin to operate until the death of the person who created the Trust as that is when the Will would take effect.

The terms of the Trust, i.e. the instructions that you give to the Trustee for future operation of the Trust may be as numerous and varied as your imagination permits in order to specifically tailor the Trust arrangement to achieve your intent. The freedom in designing your Trust arrangement is subject only to meeting certain guidelines or laws existing in the State where the Trust is created and administered.

A typical Trust arrangement in its briefest form might be summarized as follows:

> I give the sum of $25,000.00 (or 1/4 of my estate or 25% of my estate) to the Last National Bank, as Trustee, for the benefit of my son, John Smith, to be administered as follows. You may spend the principal and/or income of the Trust for vacations and recreational activities for John Smith during his lifetime as you may deem advisable. You may not spend the assets of this Trust for his basic care and support which is being provided through governmental assistance programs. When my son dies, if there are any Trust assets left, give them to his brothers and sisters.

This Trust arrangement should meet most of your concerns. Since the Last National Bank is obligated to abide by your wishes as set forth in your Trust, you can be reasonably assured that it will spend the money for vacations and recreational activities for your child and will refrain from spending the assets for his basic support and maintenance. The Trustee has no ulterior motives except to administer the Trust the way you have directed. As long as the money holds out, you can be assured that your child will be provided with vacation and recreational activities long after your death. In order to appreciate the final advantage of the Trust arrangement; you should be aware that the Trust may be structured in such a fashion so that the principal and income of the Trust estate is not considered to be the property of the beneficiary. After all, he is only entitled to receive what the Trustee decides to give him within the framework of the instructions you have given the Trustee. Furthermore, your son has only a lifetime interest in this trust and his brothers and sisters may expect to receive whatever is left in the Trust estate upon the death of the primary beneficiary. For these reasons, the government, or other creditors of your son, should not be able to reach the Trust assets to satisfy their claims. Since the law recognizes that the Trust assets, until distributed, are not the property of your son, those assets should not be taken into consideration in determining whether your child is eligible to receive governmental financial assistance such as social security benefits.

QUESTION #3 Can I achieve the same result by giving my disabled child's share to my other children with instructions to use the money for the benefit of my child with a disability? [Morally obligated gift]

This approach is full of dangers and traps which have absolutely nothing to do with the trustworthiness of your other children. With no formal Trust arrangement, the disabled child's share might very will be comingled or mixed with the assets of your other children. Should the child holding the assets be involved in a divorce, your disabled child's share might very well end up in the hands of your former son-in-law or daughter-in-law. An unexpected death could result in the disabled child's share being included and distributed as part of someone else's estate, totally defeating your intentions. The bankruptcy of the trusted child could very well wipe out the disabled child's share as well. With a formal trust arrangement, you have the full power of the Iowa District Court available to enforce the provisions of the Trust whereas in the above approach you can rely only upon the good intentions of your other children.

QUESTION #4 Who should I name as trustee? A bank or family member?

Subject to some additional qualifications set forth in the probate code, the Trustee may be a bank or an individual 18 years of age or older. The bank offers an element of stability and expertise in managing other people's assets. However, a bank trustee often lacks the personal relationship with the beneficiary and may be totally unaware of the beneficiary's particular needs. An individual family member has the benefit of that personal relationship with the beneficiary and a knowledge of the beneficiary's needs. On the other hand, if that family member does not live in the same area as the beneficiary, his or her value would be greatly diminished.

One solution would be that you direct your banker trustee to confer with other family members regarding the needs of the beneficiary. Several alternatives are available, and you should thoroughly discuss the selection of the Trustee with your attorney at the time the Trust is created.

QUESTION #5 Are there attorneys available with special knowledge regarding estate planning for parents of children with disabilities?

I am sure that there are, but I know of no practical way of finding such an attorney other than simply discussing the matter with a proposed attorney before hiring him/her. You should be aware that the estate plans discussed in this article are not unique, and that most competent attorneys who are involved in an average amount of estate planning for their clients should immediately recognize the rules that have been discussed. What they may lack is the knowledge regarding the specific needs of your child who is disabled. However, this information can be supplied by you at the time of your estate planning conference.

QUESTION #6 How can we insure that my child will receive services and residential care locally rather than being transferred to some state institution after my death?

Of course, there may be other reasons requiring such a transfer, but if the primary reason is financial, you would be in a position to anticipate this problem in your Trust. In other words, you can instruct your Trustee that in the event a payment from the Trust would make the difference between your child living in a locally operated group home versus a state institution, then the Trustee is authorized to make that expenditure.

TRUSTS

A trust is a legal relationship created by an individual in which a trustee (e.g. family members, financial institutions, etc.) holds and manages property or resources for the benefit of a third party beneficiary (e.g. individual with a disability) based upon written instructions in a document called a trust.

A trust can be established in an individual's will (testamentory trust) or by declaration of trust during the individual's lifetime (inter-vivos trust). A trust can offer many estate planning benefits to the parent of a child with special needs. A common misconception is that trusts can only be effectively used by wealthy individuals. However, the greatest use of trusts is made by individuals of modest means with special estate planning needs.

The primary concern in estate planning with regards to a family member with a disability is the possible loss of Federal or state aid (e.g. Medicaid or state assistance) due to large assets, income or resources in the possession or control of the child with a disability. In future estate planning, the parent needs to be aware of:

-- all local, state and federal programs and services available to a child with a disability

-- eligibility requirements that are based upon the individual and family's "resources" and "income" (see Supplemental Income section on what is considered "resources" or "income")

-- circumstances under which benefits, services, eligibility may be lost or become chargeable due to inheritance

Goldberg and Frank (1989) suggest consideration of four types of trusts for families who have a child with a disability. They are:

Mandatory Support Trust

"A mandatory support trust requires either (1) an income distribution (such as a fixed percentage of the income earned by the trust or a fixed dollar amount); or (2) a distribution of income or principal to fulfill a specific standard such as support, education or health needs of the beneficiary." This type of trust sounds appealing but may jeopardize eligibility for federal and state programs since the trust assets in a mandatory support trust are usually included as "resources" of the beneficiary.

Pure Discretionary Trust

A pure discretionary trust gives a trustee absolute discretion to distribute trust principal and income to a beneficiary. Since a beneficiary cannot compel distributions from a pure discretionary trust, the trust should shield assets from being used as a replacement for state or federal benefits since the trust will not be considered a "resource" of the beneficiary. However, the broad discretionary provisions given to the trustee may leave the beneficiary at the mercy of a trustee who does not distribute funds sufficient for the beneficiary's comfortable support.

Discretionary Support Trust

A discretionary support trust is a hybrid trust which combines explicit discretionary language to protect the beneficiary's benefits with support trust provisions in order to provide guidance to the trustee in making supplemental distributions.

A discretionary support trust should address the following:

1) Clearly specify that the trust is to be used to **supplement** not supplant government benefits.

2) Include a "spendthrift clause" that protects the trust against creditors.

3) Identify co-trustees such as a family member who understands the needs of the person with disabilities along with an institution that has experience in managing a trust.

4) Should be managed (or co-managed) by expert legal and trust counsel because of potential changes in trust laws.

5) Include a "self-termination clause" which will dissolve the trust if laws or circumstances change that threaten the trust.

Community Trust

A community is a trust in which the resources of a group of beneficiaries are pooled and managed by a local volunteer Board of Trustees composed of parents and professionals. A community trust is also commonly referred to as a "self-sufficiency trust". Community trust legislation is new and its effectiveness has yet to be determined in Iowa.

Factors To Consider When Establishing a Trust

Factors that should be taken into account when considering establishing a trust are:

1) Financial and personal responsibility of the trustee that will ensure that the care, needs and interests of the beneficiary who has a disability are met

2) The amount and freedom of discretion the trustee has to protect and use the resources of the beneficiary as intended

3) Explicit statements with regard to use of trust assets in replacing state or Federal aid and programs

4) Provisions for the termination of the trust and disbursement of any assets upon the death of the beneficiary who is disabled.

It is best to consult your attorney and estate planner when establishing a trust to become aware of applicable current state laws.

WILLS

A will is a written legal declaration of a person's wishes regarding the disposition of their property after death. Distribution of property and/or resources as stated in a will is handled by a probate court. The probate court determines the validity of the will and then takes steps to carry out the declarations stated in the will. If one were to die without a will (intestate) the estate is disposed of according to statutes set forth by law with portions of real and personal property going to the spouse and children. In addition to designating the distribution of property, parents can name someone they believe will be a good guardian, limited guardian or conservator for their child, if they think there will be a need for such a person after their death. In every will the testator (person making the will) should name the executor of the estate. The executor is the person responsible for collecting, maintaining and distributing assets of the estate as specified in the will. The executor can be a family member, close friend, attorney or anyone chosen by the testator. The executor does not have to be an attorney. An attorney can be hired by the executor if deemed necessary, using funds from the estate. Leaving assets to a child or adult with a disability poses some special concerns that parents will want to consider. Those concerns are:

1) Does the son or daughter possess the capacity to manage the assets?

2) Property or other assets left directly to the child with a disability could be counted as resources and may make the child ineligible for government benefits like SSI or medicaid (see Section Six on SSI Guidelines).

3) Depending on the value of the assets or property, government funded services or care may have to paid for by the child with a disability.

Each family situation, as well as the needs of the person with a disability are unique. Again, it is recommended that parents consult an attorney for current laws and regulations when developing a will.

Joint Property and Life Insurance

Beyer (1986) identified the option of jointly owned property and life insurance in estate planning in addition to wills and trusts. Parents may decide to designate their child as a joint owner of property subject to a right of survivorship. When the parent dies the child then becomes the owner of the property. This approach, according to Beyer, has the same effect and disadvantages of other resources being passed to the child through a will i.e. ability to manage, potential ineligibility for benefits and charges for care. Beyer also suggests consideration of a small joint bank account, possibly requiring two signatures for the purpose of teaching money management skills.

Life insurance is one other option that should be explored in estate planning. According to Beyer, life insurance is a contract with the life insurance company and is not affected by the parent's will unless the beneficiary is the parent's estate. Disadvantages of making the estate the beneficiary could be the possibility of increasing the cost of probating the estate as well as potential estate tax consequences. Naming the child as beneficiary creates the potential for the same disadvantages as leaving property or other direct bequests. Naming another individual as beneficiary (e.g. brother, sister, etc.) with the request that funds be used for the care and benefit of the child who is disabled poses the same concerns as a morally obligated gift (see question 3 in the Schilling article, page 16).

NEED A LAWYER BUT CAN'T AFFORD ONE?

You may be able to get FREE legal help from Legal Services Corporation of Iowa. LSCI is a non-profit program funded by Congress. Ten offices are located around the state. All counties are served except Polk County. People who live in Polk County should contact Legal Aid Society of Polk County (515) 243-1193.

Who is Eligible for Legal Help from LSCI?

You must meet LOW-INCOME GUIDELINES that LSCI is required to follow. They are based on family size, income levels and assets. Call any LSCI office for information on eligibility.

Legal Services may represent only poor people with "CIVIL" (NON-CRIMINAL) PROBLEMS. Cases cannot be accepted if a private lawyer might be able to collect a fee from the court or an opposing party.

What Kinds of Cases Does LSCI Handle?

Legal Services receives less than $9.00 for each poor person in the 98 counties we serve. Because of the small staff, not every case can be taken. Priorities have been set for the types of problems LSCI will accept. The highest priorities for LSCI are the legal problems of homeless persons and the legal problems of the rural poor. Other high priorities are listed below.

Income Maintenance

Including AFDC, Food Stamps, General Relief, Social Security, SSI, Unemployment Compensation, Veterans Benefits

Health

Medicaid, Medicare, problems in health facilities, Hill-Burton

Housing

Federally-subsidized housing rights, Eviction, Remedying Housing Defects, Housing Discrimination

Individual Rights

Including Rights of the Mentally Disabled, Rights of the Physically Disabled, Rights of Children in Confinement

Family

Family Violence

Consumer Problems

Debtor Protection, Energy/Utilities Including Shut-Offs

Note: Legal Services provided by LSCI are not limited to the areas listed above. The decision to accept a case is made at a weekly staff meeting in the office providing services to your county.

How Do I Apply for Help With a Legal Problem?

Call the LSCI office that serves your county (see next page). You will be asked questions to find out if you are eligible. If you are eligible and have a problem LSCI can handle, one of two things will happen:

1. If your case is an EMERGENCY a lawyer or paralegal will talk to you at once. (Examples: family violence, utility shut-offs, evictions).

2. If it is not an emergency, the important facts will be taken down. Later the LSCI office will discuss your case. You will then be notified if your case can or cannot be taken.

If needed, a personal interview in the office will also be scheduled. Once your case is accepted, you will be asked to sign a Client Retainer Agreement. It spells out all the ground rules for being represented by LSCI.

Do I Have To Pay Any Costs?

Legal Services does not charge a fee for the services of its lawyers or paralegals. However, the client may be expected to pay for any costs of representation such as filing fees for court papers.

Sometimes court costs are awarded in a case. They may be used to pay LSCI back for court costs it paid for you. Often there are no costs involved.

What If I Am Eligible But LSCI Cannot Take My Case?

LSCI will try to refer you someplace else for help. One possibility is the Volunteer Lawyers Project. Over 1,000 private attorneys across Iowa are Volunteer Lawyers. They have agreed to help LSCI by taking some of the cases we refer to them. They do not usually charge fees for their time. However, they may charge you for court costs, such as filing fees and other out-of-pocket expenses.

If a volunteer lawyer in your area is willing to accept your case, you will be sent a letter. It will state who the volunteer lawyer is and how you can make an appointment with that lawyer. If you do not contact the private attorney within 30 days, your case will be closed. If the volunteer lawyer agrees to take your case, you will have no more contact with the Legal Services office on that particular case. If a volunteer attorney is not available to handle your case, we will send you a letter telling you that we could not place your case with a private lawyer. You will then need to find an attorney on your own.

Note: From Need a Lawyer But Can't Afford One? Revised 1989, Legal Services Corporation of Iowa, 315 East Fifth Street, Des Moines, Iowa 50309. Printed by: Advocator Welfare Answering Service. Reprinted by permission.

Hours and Locations

Legal Services Offices are normally open Monday through Friday from 8:30 a.m. to 5:00 p.m. They are closed on holidays. You should call in advance for an appointment. To find out which regional office serves your county, call or write:

Legal Services Corporation of Iowa
315 East Fifth Street, Suite 22
Des Moines, IA 50309
Toll-Free Phone: 1-800-532-1275
or call (515) 243-2151

Addresses and phone numbers for Regional Offices in Iowa are listed below

Cedar Rapids Regional Office
Suite 400, Paramount Bldg.
305 2nd St. S.E.
Cedar Rapids, IA 52401
319-364-6108
1-800-332-0419

Southeast Regional Office
106 N. Market
Ottumwa, IA 52501
515-683-3166
1-800-452-0007

Southwest Regional Office
300 Smith-Davis Building
532 First Ave.
Council Bluffs, IA 51501
712-328-3982
1-800-422-9229

Northwest Regional Office
215 Commerce Building
520 Nebraska Street.
Sioux City, IA 51101
712-277-8686
1-800-352-0017

Northeast Regional Office
Suite 280, Nesler Center
Town Clock Plaza
Dubuque, IA 52001
319-588-4653
1-800-942-4619

South Central Regional Office
315 E. 5th St., Suite 25
Des Moines, IA 50309
515-280-3636
1-800-532-1503

Iowa City Regional Office
430 Iowa Avenue
Iowa City, IA 52240
319-351-6570
1-800-272-0008

Waterloo Regional Office
708 1st National Building
Sycamore and East Fourth
Waterloo, IA 50703
319-235-7008
1-800-772-0039

North Central Regional Office
Suite 220 Mohawk Square
Mason City, IA 50401
515-423-4651
1-800-392-0021

Help Legal Assistance
609 Putnam Building
215 Main Street
Davenport, IA 52801
319-322-6216

Legal Services Corporation of Iowa is committed to providing quality legal services to eligible low-income people. However, due to limits placed on their program, they cannot help every person who applies for service. Complaint procedures have been established for clients and members of the general public who disagree with LSCI decisions. For a detailed copy of their complaint procedures, contact any LSCI office.

LSCI Publications

Legal Services Corporation of Iowa publishes a large number of self-help and general education booklets which are available to the public for little or no cost. (Clients and low-income people receive the publications free). Some of the booklets available include:

Group Homes: The Resident's Rights ($2.50); Involuntary Transfer: Long-Term Care Facilities and Group Homes ($2.50); A Guide to Iowa Programs for Free Medical Care: State Papers and County Pay ($2.50); How To Apply For SSI ($2.50); Questions and Answers About DHS Appeals and Hearings ($2.50); Social Security and SSI: The Appeals Process ($2.50).

For a complete listing and cost guide, write to Publications, Legal Services Corporation of Iowa, 315 E. Fifth Street, Des Moines, IA 50309.

Appendix

Appendix: Family Estate Planning Inventory

ASSETS

Money
- Cash on Hand _____
- Checking Account _____
- Savings Account _____
- Certificate of Deposit _____

Real Estate (appraisal value) _____
Stocks (market value) _____
Bonds (market or accrued value) _____
Life Insurance (cash value) _____
Automobiles (market value) _____
Personal Property (household, jewelry, etc.) _____
Other

_____ _____
_____ _____

LIABILITIES

Credit Cards _____
Loans _____
Home Mortgage _____
Others _____

As much of the following information as possible, should be attached to the will.

Mother's Social Security Number _____
Father's Social Security Number _____
Military Serial Number of Veteran's "C" Numbers _____
Railroad Retirement number _____
Civil Service Employment Number _____

Banks, Savings Accounts, Checking Accounts (by location and number)
#_____ #_____
_____ _____

#_____ #_____
_____ _____

Safety Deposit Boxes (locations and numbers of boxes)
#_____ #_____
_____ _____

List Insurance Policies - Life & Medical (Policy Numbers)
#_____ #_____
_____ _____

List Interested Relatives

Name _____ Name _____
Address _____ Address _____
_____ _____
Phone _____ Phone _____

Name _____ Name _____
Address _____ Address _____
_____ _____
Phone _____ Phone _____

Any other information that you feel would help an executor or guardian to do his or her duties in assisting a son or daughter who is handicapped.

_____
_____
_____
_____

Note: From Estate Planning for Families with Developmentally Disabled Children, Iowa Developmental Disabilities Council. Reprinted by permission.

Appendix: Sample of a Simple Will

LAST WILL AND TESTAMENT OF JOHN R. DOE

I, JOHN R. DOE OF Omaha, Douglas County, Nebraska, declare this to be my Last Will and Testament and direct the following disposition be made of my estate.

1. I direct that all expenses of my last illness and funeral be paid as soon after my death as conveniently may be done.

2. I give, bequeath and devise all of my estate, real and personal, in which I have any interest at the time of my death not otherwise effectively disposed of, to my wife, BARBARA DOE, if she survives me by thirty (30) days.

3. In the event my wife, BARBARA DOE, does not survive me by thirty (30) days, I then direct that my estate be divided equally amongst our three children, CHAD DOE, RYAN DOE, and JENNIFER DOE and any other child that may be born to or adopted by my wife, BARBARA DOE, and me. If any of our children do not survive me, his or her share of my estate shall then pass to his or her issue by right of representation.

4. I appoint my wife, BARBARA DOE, Personal Representative of my estate and I direct that no bond be required of her as my Personal Representative, and said Personal Representative or any person or corporation appointed in her place and stead, shall have full power, authority and discretion to do any and all things necessary for the complete administration of my estate, including the power to sell at public or private sale, and without order of any Court, any and all real or personal property belonging to my estate, and to settle and adjust any and all claims, debts and demands against or in favor of my estate, as fully as I could do if living.

IN WITNESS WHEREOF, I have hereunto set my hand this _____ day of _____, 19____, in the presence of the persons whose names are subscribed below as attesting witnesses and who signed this will as witnesses in my presence and at my request.

_____

John R. Doe, Testator

On the date last above written, JOHN R. DOE, known to us to be the person whose signature appeared at the end of this will, declared to us, the undersigned witnesses, that the foregoing instrument was his will and that he was acting voluntarily and of his own free will in the execution thereof. He then signed the will in our presence, and at his request and in his presence and in the presence of each other, we now sign our names as witnesses.

_____ residing at _____
(signature) (street, city, state)

_____ residing at _____
(signature) (street, city, state)

Note: From Estate Planning for Families with Developmentally Disabled Children, Iowa Developmental Disabilities Council. Reprinted by permission.

IOWA PROTECTION AND ADVOCACY SERVICES, INC.
3015 Merle Hay Road, Suite 6
Des Moines, IA 50310
515-278-2502

Order Form

Title	Quantity	Price	Cost
Protection and Advocacy Developmental Disabilities Brochure	_____	Free	_____
Protection and Advocacy Mental Illness Brochure	_____	Free	_____
Legal Settlement Brochure	_____	$ .15/each	$_____
Involuntary Discharges of Transfers Brochure	_____	$ .15/each	$_____
Guide to Guardianships and Conservatorships Brochure	_____	$ .90/each	$_____
Parents Involved - A Guide to the Individualized Education Program Booklet	_____	$2.50/each ($1.50/each for orders of 10 or more)	$_____ $_____
Estate Planning Packet: (includes the following) * Developmental Disability Brochure * Mental Illness Brochure * Legal Settlement * Involuntary Discharge * Guardianship * Handouts - copied * Pocket Guide to Federal Help for Individuals With Disabilities	_____	$2.90/each	$_____
		TOTAL COST:	$_____

RESOURCES & REFERENCES

Planning for the Future

Ann Hart Wernz, Esq. (1984). Planning for the Disabled Child. (Available from The Northwestern Mutual Life Insurance Company, 212 Insurance Exchange Building, Des Moines, Iowa 50309)

> Provides an outline of the problems requiring special attention for parents making plans for adults or children with disabilities. Also offers suggestions for personal care and financial assistance of the individual with a disability after the parents' deaths. This pamphlet is one of the resources that deals with insurance as part of the available estate planning tools for disabled children.

ARC National Insurance and Benefits Committee (1984). How to Provide for their Future. Arlington, TX: Association for Retarded Citizens.

> The authors have tried to show the interrelationship between the child's prospective needs for social and/or economic supports, as individually assessed, and the formal mechanisms which can be brought to bear on them--insurance, trust provisions, governmental benefits for the disabled and guardianship. The chapters are: Guardianship, Wills, Trusts and General Estate Planning, Insurance Benefits, and Governmental Benefits.
> Cost: $3.00.

Beyer, H.A. (December, 1986). Estate Planning: Providing for Your Child's Future. The Exceptional Parent, pp. 12-15.

Center for Law and Health Sciences. (1986). Estate Planning for Parents of Persons with Developmental Disabilities. (Available from Disability Law Center, Inc., 11 Beacon Street, Suite 925, Boston, MA 02108).

> This booklet is written to assist parents of disabled persons in planning their estates. Topics covered include: Inheritance, Life Insurance, Property, Trusts, Guardianship, Conservatorship, Representative Payee and Banking Arrangements. An appendix is included that describes Government Benefits and Services such as SSI, Medicaid, Social Security, Veterans Benefits and Vocational Rehabilitation.

Beyer, H.A. (December, 1986). Estate Planning: Providing for Your Child's Future. The Exceptional Parent, pp. 12-15.

Estate Planning for the Disabled. P.O. Box 808, Manteca, CA 96336-0808, (209) 239-7558 or (916) 928-1400.

> EPD is a nonprofit corporation, which counsels and assists parents of special needs children to develop (at the lowest possible cost) estate plans, letters of intent, wills and special needs trusts. Estate teams consisting of a planner, attorney, and a CPA have been organized in several California locations and elsewhere in the country. Special payment plans and discounts are available to low-income families. Seminars, workshops and resource lists are among the services offered. Callers from other states will be assisted or referred to appropriately trained and experienced attorneys and financial specialists.

Fruge, D.L. & Green, K.O. (1982). Estate Planning for Retarded Persons and Their Families. Atlanta, GA: Mississippi Department of Mental Health.

Goldberg, I.V. & Frank, A.L. (1989). Estate Planning to Meet the Special Needs of a Severely Disabled Child. Estate Planning, pp. 232-236.

Parental Self Assessment: Assuring Future Care of Disabled Dependents. (1987, Summer) WAYS, pp. 6-11.

> Provides parents with planning checklists that deal with necessary future planning documents (Will, Trust, Letters of Direction) and services (adult daily living, health care, vocational/day training, financial management, general advocacy services, residential services and others).

Russell, L.M. (1976). Alternatives: A Family Guide to Legal and Financial Planning for the Disabled. Evanston, IL: First Publications.

> As an attorney with a mentally handicapped brother, the author addresses such questions as: Does my child need a legal guardian? Am I taking advantage of all the possible medical deductions and credits I am entitled to receive? What is the easiest way of obtaining medical insurance for my handicapped child? Chapter titles are: Wills, Guardianship, Trusts, Government Benefits, Taxes, Insurance and Financial Planning. $11.95. (Gives questions, not answers).

Turnbull, H.R., Turnbull, A.P., Bronicki, G.J., Summers, Jean Ann, & Roeder-Gordon, C. (1989). Disability and the Family: A Guide to Decisions for Adulthood. Baltimore: Paul H. Brookes.

Section Three
GUARDIANSHIP AND CONSERVATORSHIP

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GUARDIANS AND CONSERVATORSHIP

What is the Difference Between a Guardian and a Conservator?

A Guardian is the legal term given to an individual who is court appointed to make decisions for another person, whom the court calls a "ward". A Guardian is appointed to make decisions and take care of the ward when a court has found that the ward is unable to make decisions in his/her life that are in the ward's best interests.

A Conservator is the legal term given to an individual who is court appointed to make decisions for another person, the "ward", only in matters relative to the ward's property or finances.

Although a guardian and conservator perform different functions, the same person can serve as both. A petition for the appointment of a guardian and conservator may be combined and thus requested at the same time.

Assessing The Need for a Guardianship or Conservatorship

Guardianships and conservatorships are initiated for protection. In determining their necessity, it is important for all persons to be aware of and understand a person's legal and human rights so that a guardianship and/or conservatorship will not restrict a handicapped person's personal liberty. If persons understand and accept that the rights to vote; marry; have children; enter into a contractual agreement; to be free from cruel and unusual punishment; to due process and equal protection under the law; privacy; to direct one's life activities; choose where to live; and who to associate with as friends belong to all citizens, including individuals who are handicapped, the need for guardianship and/or conservatorship will be more thoroughly assessed.

It is also significant that in assessing the need for a guardianship and/or conservatorship, community acceptance through integration and normalization is understood to be a basic right of all persons. All individuals are born into an integrated society. Persons with disabilities have the right to participate in the experiences that life presents to all of us, its successes, its failures, the opportunity to know what "living life to its fullest" means. This means allowing persons with disabilities to maintain their autonomy and decision-making power to the maximum extent possible.

Questions To Consider

1) What is the current mental and physical functioning level of the individual who is handicapped? Is the current level likely to increase or decrease? What are the specific areas of concerns (i.e. medical, social, emotional, educational, etc.)?

2) Are there other steps that can be taken at the present time that will allow for the person who is handicapped to maximize his/her potential for independence and self-sufficiency?

3) Is the person who is handicapped a minor? (In Iowa, a minor is an individual under the age of 18).

4) What decisions will need to be made in the future on behalf of the individual who is handicapped? Can the person who is handicapped make that decision alone? If not, what type of assistance does he/she need?

5) What types of decisions can the person who is handicapped make on his/her own?

6) What types of decisions does the person who is handicapped need help with and to what extent?

7) Why consider guardianship and/or conservatorship? Is it necessary?

8) Is a guardianship and/or conservatorship being suggested for convenience only, or is it in the best interest of the individual who is handicapped?

9) Is there an alternative other than a legal guardianship or conservatorship? Are there friends, relatives or family members who can assist the person who is handicapped in a decision-making process?

10) Is there a specific problem(s) that the appointment of a guardian and/or conservator will resolve? Is there the possibility of danger to the person who is handicapped such as a mental/physical neglect or abuse by either himself/herself, or others?

Issues To Consider

The imposition of a guardianship and/or conservatorship results in the loss of rights and decision-making power for the person with the disability. Therefore, the individual's abilities and needs must be considered as primary in the decision to seek guardianship and/or conservatorship or other less restrictive means to resolve any concerns. All of us rely on friends, family, and professionals for advice from time to time. We each encounter situations that require us to make difficult decisions and so we look to others to help us make informed decisions. This means that we attempt to collect as much information as possible from different sources so that we can have a better understanding of the circumstances surrounding a decision we must make.

For some persons with handicaps, knowing that they have a friend, family member, advisor, or professional, who will help them in making decisions at various times, may and will be sufficient. In these situations, no court intervention, such as the appointment of a legal guardian or conservator, is necessary and the rights of the individual are most likely to be protected.

Liability of Guardians and Conservators

Guardians and conservators shall not be held personally liable for actions or omissions taken or made in the official discharge of the guardian's or conservator's duties, except for any of the following:

1) A breach of legal duty imposed by the court.

2) Willful or wanton misconduct in the official discharge of the guardian's or conservator's duties.

Note: From A Guide to Guardianships and Conservatorships, (1988). Iowa Protection & Advocacy Services, Inc., Des Moines, Iowa. Reprinted by permission.

GUARDIANSHIPS

In Iowa there are four types of legal guardianships. Court approval is necessary. Rights that are not limited or restricted by the court are legally retained by the individual.

1) **Stand By**
Any person of full age and sound mind may execute a verified petition* for the voluntary appointment of a guardian upon the express condition that the petition shall be acted upon by the court only upon the occurrence of an event specified or the existence of a described condition of the mental or physical health of the petitioner. The stand-by petition must specify the conditions or events that must occur to activate the guardianship. The petition may be revoked by petitioner at any time prior to appointment of a guardian if the petitioner is of sound mind.

*A verified petition is a document provided to the court, under oath, indicating that the contents of the document are true.

Example: Tim is a physically disabled adult who's disability will progress in severity. Tim voluntarily agrees now to the appointment of a guardian when his condition reaches a specified point whereby he feels he needs a guardian to assist him.

2) **Temporary**
The intent of a temporary guardianship is to provide a guardian for only a certain amount of time. However, these types of guardianships are quite restrictive as the law does not specify a time limit in the number of days and/or weeks upon which the temporary guardianship must terminate.

Example: Kathy has a disability that requires frequent hospitalizations. A temporary guardianship has been imposed that states she has a guardian "as long as the ward is hospitalized." Thus, the duration of this particular guardianship operates only while Kathy is in a hospital.

3) **Limited**
A limited guardianship permits a guardian to have only certain powers over the ward. The court will set forth those powers that belong to the guardian. All others not established by the court are to be retained by the ward.

Example: Steve is an adult with mental retardation. Steve is under a limited guardianship, whereby his guardian assists him in making a decision about appropriate and least restrictive placement in a residential facility.

4) **General**
A general guardianship is the most restrictive of all the guardianships established under Iowa law. This type of guardianship permits a guardian to make and carry out important decisions relating to the general affairs, other than financial, of the person who is handicapped.

Example: Cindy is a severely mentally and physically handicapped adult. A general guardianship is been imposed whereby Cindy's guardian can make most decisions on her behalf without court approval. Exceptions to this general rule are where Cindy's guardian has arranged for major elective surgery or other nonemergency major medical procedures, or where Cindy's guardian wishes to move Cindy's place of residence to a more restrictive environment. Thus, court approval is required in these circumstances.

Voluntary vs. Involuntary

A guardianship can be initiated through either a voluntary or involuntary procedure. From an advocates' perspective, a voluntary guardianship is one whereby the ward understands fully and clearly his/her need for a guardianship and therefore requests that a guardian be appointed. All others are involuntary.

Voluntary Petition

A guardian may be appointed by the court upon the verified petition of the proposed ward, without further notice, if the proposed ward is other than a minor under the age of fourteen years, provided the court determines that such an appointment will be in the best interest of the proposed ward.

In guardianships involving minors, parents are the preferred guardians over all others, if they are qualified and suitable. Preference is next given to any person, if qualified and suitable, who has been nominated as guardian for a minor child by a will executed by the parent having custody of a minor child, and then by any qualified and suitable person requested by a minor fourteen years of age or older. Subject to these preferences, the court shall appoint any qualified and suitable person who is willing to serve in that capacity.

Voluntary proceedings do not require a hearing, an examination of the proposed ward, or notice. However, the court shall ensure that all proposed wards entitled to representation have been provided with notice of the right to representation and their right to be personally present at all proceedings. In many instances, it is possible to obtain the order appointing guardianship at the same time that the petition is filed. Also, there is no right to a court appointed attorney in voluntary proceedings.

Involuntary

Proceedings involving guardianships require that a third person, not the proposed ward, take the initiative to ask the court to appoint a guardian.

The third party must file a petition with the court. The contents of the petition must contain the following information:

1) The name, age, and post-office address of the proposed ward.

2) That the proposed ward is either:

   a) by reason of mental, physical or other incapacity unable to make or carry out important decisions concerning their personal affairs, other than financial. (A person who makes or carries out decisions concerning a person's financial affairs is called a "Conservator".)

   b) a minor.

3) The name and post-office address of the proposed guardian and that such person is qualified to serve in that capacity.

4) That the proposed ward is a resident of the state of Iowa or is present in the state, and that the ward's best interests require the appointment of a guardian in this state.

5) The name and address of the person or institution, if any, having the care, custody or control of the proposed ward.

Notice

Legal notice of the filing of the petition must be served upon the proposed ward. Within twenty days after the receipt of this notice, the proposed ward must respond. If the proposed ward is a minor and entitled to legal representation, notice given to the court appointed attorney is sufficient.

Hearing

After notice is served and the proposed ward responds, the court will schedule a time and place for a hearing to be held to determine the need for a guardian. The proposed ward also has the right to be present at the hearing.

Legal Representation

A proposed ward has the right to an attorney during involuntary guardianship proceedings if he/she is an adult and is not the petitioner. If the proposed ward is a minor or an adult, the court shall determine whether, under the circumstances of the case, the proposed ward is entitled to representation and is indigent or incapable of requesting legal representation. If such is the case, the court shall appoint an attorney to represent the proposed ward.

Burden of Proof

In Iowa, the law presumes that every individual is capable of taking care of his/her own affairs. Therefore, if someone feels otherwise about a person who is handicapped, he/she has the "burden" to show the court the need for a guardian/conservator. This means that the person requesting the imposition of the guardianship must prove that the person who is handicapped is unable to take care of his/her own affairs. If the allegations of the petition as to the status of the proposed ward and the necessity for the appointment of a guardian are approved, the court may appoint a guardian. Individuals seeking imposition of a guardianship of an individual who is handicapped should give careful consideration to who would be appointed as guardian. Although a family member may know the handicapped person better than most other persons, consideration must be given to the fact that family members have an emotional bond with the person who is handicapped that could create a tendency for over-protection. A guardian needs to be objective in his/her point of view so that the individual's rights are not violated or unnecessarily restricted.

Guardian Responsibilities

A guardian must at all times act in the "best interest" of the ward. The guardian has certain responsibilities specified under Iowa law:

Court Approval Required:
A guardian must obtain court approval before the guardian:

1) Changes the ward's permanent residence if the proposed new residence is more restrictive of the ward's liberties than the current residence.

2) Arranges for major elective surgery or any other non-emergency major medical procedure.

Court Approval Not Required:
Court approval is not required of the guardian in the following instances:

a. Providing for the care, comfort and maintenance of the ward, including the appropriate training and education to maximize the ward's potential.

b. Taking reasonable care of the ward's clothing, furniture, vehicle, and other personal affects.

c. Assisting the ward in developing maximum self-reliance and independence.

d. Ensuring the ward receives professional care, counseling, treatment or services as needed.

e. Any other powers or duties the court may specify.

Guardian Reports

A guardian must file the following written verified reports with the court:

a. An initial report within sixty days of the guardians appointment.

b. An annual report, unless good cause is shown and the court otherwise orders.

c. A final report within thirty days of the termination of the guardianship unless that time is extended by the court.

The reports required include:

a. The current mental and physical condition of the ward.

b. The present living arrangement of the ward, including a description of each residence where the ward has resided during the reporting period.

c. A summary of the medical, educational, vocational and other professional services provided for the ward.

d. A description of the guardian's visits with and activities on behalf of the ward.

e. A recommendation as to the need for continued guardianship.

f. Other information requested by the court or useful in the opinion of the guardian.

The clerk of court is to notify the guardian in writing of the reporting requirements and provide information and assistance to the guardian in filing the reports. A district court judge or referee will review and approve the reports. Simplified forms are available from the clerk of court.

When Does a Guardianship End?

A guardianship will terminate upon the occurrence of any of the following circumstances:

1. If the ward is a minor, when the ward reaches age 18.

2. The death of the ward.

3. A determination by the court that the ward is competent and capable of managing his/her own affairs, and that the continuance of the guardianship would not be in the ward's best interests.

4. Upon determination by the court that the guardianship is no longer necessary for any other reason.

At any time, the person under guardianship may apply to the court by petition, alleging that he/she is no longer in need of a guardian and thereby asks the court to terminate the guardianship. (Note: The requirement of a six month waiting period before the person under guardianship can petition to terminate the guardianship no longer exists.)

The court can remove a person as guardian if he/she is not acting in the best interests of the ward. An example of this is where the guardian is not carrying out his/her duties.

The person under the guardianship, other interested persons, or the court, may file a petition with the court requesting the removal of a guardian.

Note: From A Guide to Guardianships and Conservatorships, (1988). Iowa Protection & Advocacy Services, Inc., Des Moines, Iowa. Reprinted by permission.

CONSERVATORSHIPS

Even though the functions of a guardian and conservator are distinct, there are many similarities in Iowa law relative to their types and procedures. For example, similar to guardianships, there are four types of conservatorships: limited, stand-by, temporary, and general. As with a guardianship, only a stand-by conservatorship is obtained voluntarily - all others can be obtained either through voluntary or involuntary procedures.

There are also similar filing, notice, hearing, legal representation, and burden of proof requirements.

Conservator Responsibilities

It is the duty of the conservator of an individual's estate to protect, preserve, and invest it prudently. The conservator has certain responsibilities under Iowa law:

Court Approval Required:

A conservator must obtain court approval:

1. To invest the funds belonging to the ward.

2. To execute leases.

3. To make payment to, or for the benefit of, the ward in any of the following ways.

   a. Directly to the ward.
   b. Directly for the maintenance, welfare and education of the ward
   c. To the legal guardian of the ward.
   d. To anyone who at the time shall have the custody and care of the person of the ward.

4. To apply any portion of the income or of the estate of the ward for the support of any person for whose support the ward is legally liable.

5. To compromise or settle any claim by or against the ward or the conservator, to adjust, arbitrate or compromise claims in favor of or against the ward or the conservator.

6. To do any other thing that the court determines to be to the best interests of the ward and the ward's estate.

Court Approval Not Required:

The conservator shall have the full power, without prior order of court:

1. To collect or receive receipt for any principal or income, and to enforce, defend against or prosecute any claim by or against the ward or the conservator and to sue on behalf of and defend claims in favor or against, the ward or the conservator.

2. To sell and transfer personal property of a perishable nature and personal property for which there is a regularly established market.

3. To vote at corporate meetings in person or by proxy.

4. To receive additional property from any source.

5. Notwithstanding certain provisions, to continue to hold any investment or other property originally received by the conservator, and also increase it, pending a timely filing of the first annual report.

Rights and Title of Ward

1. The ward shall be given notice that clearly advises the proposed ward of the right to counsel and the potential deprivation of the proposed ward's civil rights.

2. All proposed wards entitled to representation shall be provided with notice of the right to representation and their right to be personally present at all proceedings.

3. A ward does not have the power to convey, encumber or dispose of property unless specified by the court.

4. The title to all property of the ward is with the ward. The right of possession is with the conservator, and subject to the control of the court.

Conservator's Reports

A conservator must file with court:

a. An inventory within sixty days of the conservator's appointment. A supplemental inventory must be filed within 30 days of additional property coming into the possession of the conservator.

b. Written verified reports and accountings as follows:

   1) Annually unless the court otherwise orders or good cause is shown.

   2) Within thirty days following the date of removal.

   3) Upon filing resignation and before the resignation is accepted by the court.

   4) Within sixty days following the date of termination.

   5) At other times as the court may order.

The reports shall include the following information:

1. The balance of funds on hand at the close of the last previous accounting, and all amounts received from whatever source during the period covered by the accounting.

2. All disbursements made during the period covered by the accounting.

3. Any changes in investments since the last previous report.

4. The amount of the bond and the name of the surety on it. (A conservator must post a bond as set by the court).

5. The residence or physical location of the ward.

6. The general physical and mental condition of the ward.

7. Such other information as shall be necessary to show the condition of the affairs of the conservatorship.

The clerk of court shall notify the conservator in writing of the reporting requirements. The reports of conservators shall be reviewed and approved by a district court judge or referee.

When Does a Conservatorship End?

A conservatorship will terminate in circumstances similar to a guardianship. In addition, if at any time the assets of the ward's estate do not exceed the amount of the charges and claims against it, the court may direct the conservator to proceed to terminate the conservatorship.

DID YOU KNOW?

1. Appointment of a guardian or conservator does not constitute an adjudication that a person is of unsound mind.

   Iowa law presumes one is competent, even if involuntarily committed for a mental illness or substance abuse.

2. If you are a minor and you have a legal guardian, when you reach the age of majority (18), your guardianship automatically ends.

3. The fact that a person is a conservator or guardian does not in and of itself make that person personally liable for damages for acts of the ward.

4. The court is responsible for approving fees in guardianship and conservatorship matters.

CONCLUSION

The decision to seek a guardian and/or conservator is one that requires careful consideration. At all times, the person who may be placed under a guardianship and/or conservatorship must be allowed the opportunity to express his/her feelings on whether one is needed, if needed, for what reason, who should be appointed and how long it is likely to be necessary.

The opportunity for freedom of expression is a right of all individuals and therefore must be protected for all.

Note: From A Guide to Guardianships and Conservatorships, (1988). Iowa Protection & Advocacy Services, Inc., Des Moines, Iowa. Reprinted by permission.

FOR MORE INFORMATION

For more information on Guardianships and Conservatorships, you may contact the Iowa Protection and Advocacy's main office at 3015 Merle Hay Road, Suite 6, Des Moines, IA 50310. Telephone (515) 278-2502. Branch office DD/MI Clinical Law Project at the University of Iowa College of Law, Iowa City, Iowa 52242. Telephone (319) 335-9023.

Note: This information is not a substitute for legal advice. You should contact an attorney for current laws of if you have questions regarding the material discussed in this section.

NEW LEGISLATION ENACTED IN IOWA 1989

Local and State Emergency Medical Boards

Each county in Iowa may establish and fund a local emergency medical board. The local board should be made up of medical professionals and lay persons. The purpose of the Board would be to act as a surrogate decision maker for patients incapable of making their own medical care decisions, but who do not have a court-appointed guardian. Such medically necessary decisions made by a Local Emergency Medical Board, or State Emergency Medical Board if no local board exists, could show and constitute cause for filing a petition in the district court for appointment of a guardian.

Training for Guardians and Conservators

The Department of Human Services will be developing training aids designed to assist all duly appointed guardians and conservators in understanding their legal duties and liabilities, the special needs of the individual who is handicapped, and how to best serve that individual and his/her interests. These materials are expected to be available in the Spring of 1990. For more information contact either the County Attorney or the Department of Human Services office in your county.

RESOURCES & REFERENCES

Planning for the Future

A Guide To Guardianships and Conservatorships (1988). Iowa Protection & Advocacy Services, Inc., 3015 Merle Hay Road, Suite 6, Des Moines, IA 50310.

ARC National Insurance and Benefits Committee (1984). How to Provide for their Future. Arlington, TX: Association for Retarded Citizens.

> The authors have tried to show the interrelationship between the child's prospective needs for social and/or economic supports, as individually assessed, and the formal mechanisms which can be brought to bear on them--insurance, trust provisions, governmental benefits for the disabled and guardianship. The chapters are: Guardianship, Wills, Trusts and General Estate Planning, Insurance Benefits, and Governmental Benefits.
> Cost: $3.00.

Center for Law and Health Sciences. (1986). Estate Planning for Parents of Persons with Developmental Disabilities. (Available from Disability Law Center, Inc., 11 Beacon Street, Suite 925, Boston, MA 02108).

> This booklet is written to assist parents of disabled persons in planning their estates. Topics covered include: Inheritance, Life Insurance, Property, Trusts, Guardianship, Conservatorship, Representative Payee and Banking Arrangements. An appendix is included that describes Government Benefits and Services such as SSI, Medicaid, Social Security, Veterans Benefits and Vocational Rehabilitation.

Fruge, D.L. & Green, K.O. (1982). Estate Planning for Retarded Persons and Their Families. Atlanta, GA: Mississippi Department of Mental Health.

Russell, L.M. (1976). Alternatives: A Family Guide to Legal and Financial Planning for the Disabled. Evanston, IL: First Publications.

> As an attorney with a mentally handicapped brother, the author addresses such questions as: Does my child need a legal guardian? Am I taking advantage of all the possible medical deductions and credits I am entitled to receive? What is the easiest way of obtaining medical insurance for my handicapped child? Chapter titles are: Wills, Guardianship, Trusts, Government Benefits, Taxes, Insurance and Financial Planning. $11.95. (Gives questions, not answers).

Turnbull, H.R., Turnbull, A.P., Bronicki, G.J., Summers, Jean Ann, & Roeder-Gordon, C. (1989). Disability and the Family: A Guide to Decisions for Adulthood. Baltimore: Paul H. Brookes.

Section Four

HEALTH CARE COVERAGE, RESOURCES AND FINANCING

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THE MAJOR TYPES OF HEALTH CARE COVERAGE

The major types of health care coverage are:

*Health Maintenance Organizations (HMOs)

*Traditional fee-for-service insurance policies and

*Preferred Provider Organizations (PPOs)

HMO

"HMOs offer prepaid health care. A fixed premium is set no matter how few or how many services are used. By paying a monthly fee, you join an HMO that covers almost all doctor, hospital and laboratory needs. Deductibles, co-payments and co-insurance are generally minimal or not required, except for certain services (e.g. mental health treatment). Providers are limited to those belonging to the plan unless specifically exempted.

PPO

PPOs allow you to choose from a list of doctors or hospitals that have agreed to give you a discount. In some cases, members pay a small fee, say $5.00, for an office visit. Charges may be paid in full for pre-approved hospital stays, surgery, X-rays and laboratory expenses.

If you use doctors or hospitals that are not Preferred Providers, the plan may pick up only 80 percent of the cost." (Voss, 1987).

Traditional Plans

Under traditional health insurance plans, the physician receives a specific fee for each service provided. Payment is generally at the time of treatment and reimbursement is made to the insured unless the physician or hospital agrees to bill the insurer directly. The insurer covers the full costs after you have paid a portion of the costs up to the annual deductible (usually a set dollar amount). You have a greater choice of physicians, hospitals and other health care providers.

Note: From Voss, M. (1987, Nov. 15). The Health Care Insurance Puzzle Des Moines, IA: Des Moines Sunday Register, 3E and McManus, M.A. (1988). Understanding Your Health Insurance Options: A Guide for Families Who Have Children With Special Health Care Needs. Association for the Care of Children's Health, 3615 Wisconsin Avenue, Washington, D.C.

PRIMARY FACTORS IN MAKING HEALTH CARE DECISIONS

Four primary factors that influence health care insurance decisions are:

1) family's current and future need for medical care

2) experience with current or previous health insurance plans and providers

3) access to appropriate and needed medical care and

4) financial resources to meet medical care needs

REVIEWING YOUR FAMILY'S HEALTH CARE NEEDS

The following questions/concerns should be addressed and answered as you begin to make a decision on the health care coverage plan that is best for your family:

General Questions

1) Are you eligible for public and/or private insurance?

2) Are you currently insured in a private individual or group plan? (Group plans are generally through employers, unions, associations, etc. and are generally cheaper than private individual plans.)

3) Have you reviewed health services used by your family during the past year? Is a similar pattern for the coming months expected? (Meet with your child's pediatrician and other health care physicians to discuss current and projected health care needs for all family members).

Enrollment Questions

1) Are there limits on enrollment such as waiting periods, pre-existing condition clauses, dependent age cut-offs? (Some cover children to age 26; others only until age 22 or younger).

2) Is there a guarantee for renewal each year as long as premiums are paid on time?

3) Are there provisions for continued coverage in case of job loss, death, divorce, part-time employment, loss of dependent child's status (dependent age cut-off)?

4) If your spouse is insured, how will your plan supplement their plan? Who submits claims? Can plans be changed? How often?

Benefits

1) What benefits are covered?

- full hospital and physician benefits
- long term care in skilled intermediate care facilities
- outpatient and home care

- "full service" (full service benefits determine payable benefits on basis of medical necessity)
- "indemnity benefits" (indemnity benefits pay a fixed amount per day for services, i.e. hospitalization)
- preventive care
- routine office visits or check-ups
- well baby care, immunizations
- cost sharing arrangements for certain services (e.g. mental health)
- benefits provided out of one's geographic area or state

2) What limits are placed on these and other benefits?

3) Is there flexibility and/or exceptions for children with special health care needs?

Costs

1) What will the insurance plan and covered services cost? Costs may include:

- premium or cost of the insurance policy
- deductible or dollar amount you must pay each year before the plan begins to pay
- co-insurance or percentage (e.g. 20%) for some or all medical services used
- co-payment or dollar amount for some or all medical services used (e.g. $2 per prescription drug)
- costs of benefits not covered by the plan (e.g., well child visits)

2) What are your catastrophic protections? Many plans set an annual stop-loss protected dollar limit after which you will no longer have to pay for covered services (e.g. $1,500). Many also set a lifetime maximum limit (e.g. $1 million) per family member, after which the plan will no longer cover you. **It is very important to have both of these catastrophic protections in your plan**. The lower the annual stop-loss protected amount and the higher the lifetime maximum, the better.

Participating Health Provider Questions

1) Ask your primary physician if he/she participates in the private or public insurance plan(s) that you are considering. If your physician does not participate in the plan, ask the following:

- Can you see the same pediatrician for most of your visits?
- Is there a choice of pediatricians available in the plan?
- Are the participating pediatricians board certified?
- Is the location of the pediatricians and other plan facilities close to home or work or school?
- Are the plan's pediatricians and facilities available for emergency, after-hours, and weekend care?
- What restrictions are placed on the referral of children to pediatric subspecialists, allied health professionals, and special hospitals that treat children?

Note: From McManus, M.A. (1988). Understanding Your Health Insurance Options: A Guide for Families Who Have Children With Special Health Care Needs. Association for the Care of Children's Health, 3615 Wisconsin Ave., Washington, D.C. $2.75 plus $1.00 for shipping/handling.

Checklist for Private Insurance, HMOs, General Health Care

Below are questions and checklists that can be used in comparing Private Insurance, HMOs, and General Health Care

I. Private Insurance Checklist for Families

Inpatient Hospital Coverage:

1. What services are covered?
2. Are there any co-payments?
3. Are there deductibles? What is the amount (individual and family)?
4. Are there any prior authorization (approval) procedures to be followed for needed services not usually covered?
5. How many days in the hospital are covered?
6. Will exceptions be made to the policy if services are deemed necessary by the primary physician?
7. Are there any pre-existing condition clauses limiting coverage?

Outpatient Services and Home Care Coverage:

1. What types of providers' services will be covered?
2. How many hours?
3. How many visits? How is "visit" defined?
4. Is there a minimum or maximum number of hours or dollars in outpatient services or home care coverage?
5. Are there restrictions regarding home care such as: (a) registered nurse only/registered nurse only at eight-hour shifts; or (b) Medicare-certified home health agency only?
6. Must home care coverage start within a designated number of days of hospital discharge and be completed within so many days? Will this be covered 100 percent? What are the coinsurance requirements?
7. What is the family deductible per calendar year?
8. What has been paid by your family toward your calendar year deductible as of the present date?
9. Is there an 80/20 coinsurance requirement up to a specified dollar amount per calendar year, after which the insurer covers 100 percent of the charges or costs? What is the dollar amount?

10. Is there a lifetime maximum? Does this include hospital coverage or only outpatient services/ home care nursing services, etc?

11. What has been expended to date toward that lifetime maximum?

12. Is there major medical coverage?

13. What services are included in the major medical coverage?

14. Is there a preferred provider option? Are there exceptions to using the preferred provider?

15. Does this policy contain a catastrophic illness clause?

16. Are there any exclusionary clauses (e.g. experimental drugs or treatments, tests)?

17. Can you purchase a supplementary benefits package? Can this include services which are not currently covered?

18. Are the following services covered under your current policy or can they be purchased under a supplemental policy or policies:

    a. adaptive equipment: prone standers___; corner tables___; specialized car seats___; bath aids___; van adaptation___;

    b. medications___; tracheostomy tubes___; gastrostomy tube___; feeding bags___;

    c. wheelchairs___; how often can they be replaced___;

    d. corrective shoes___'

    e. eyeglasses___; lens replacement___;

    f. specialized orthodontia___;

    g. braces___;

    h. prosthetic devices___;

    i. respite care___;

    j. genetic services___;

    k. hospice___;

    l. speech, language and hearing___; physical therapy___; occupational therapy___;

    m. mental health services___;

    n. homemaker/home health aide___;

o. attendant services___;

p. nutrition services___;

q. rehabilitation services___;

r. infant stimulation programs___;

s. counseling programs: parents___; peers___; patient___

t. case management___;

u. durable medical equipment___; ventilators___; suctioning___; IV stands___; air compressors___; feeding pumps___?

19. How does the insurance policy define and how does the company determine what is:

a. usual and customary;

b. experimental;

c. therapeutic;

d. custodial;

e. medically necessary?

II. Evaluation of HMOs: A Checklist for Families

Questions to ask an HMO

In addition to the questions listed above, these questions should be asked of an HMO:

1. a. What are the procedures and restrictions on obtaining referrals to specialty providers affiliated with the HMO?

b. What are the procedures and restrictions on obtaining referrals to specialty providers not affiliated with the HMO?

c. Are subscribers usually granted their requests for referral?

d. How long does it take to get a decision on a request for a referral?

e. Who must approve referrals?

f. How are denials of referrals appealed?

2. Are all the providers listed on the HMO roster available to all subscribers? If not, what are the restrictions?

3. a. Does the HMO have contracts with hospital(s)? Which hospitals(s)?

   b. Which HMO physicians have staff privileges at which of these hospitals?

4. If a subscriber selects a primary care physician who is with a particular clinic or individual practice association, will a subscriber be restricted to specialists who are members of that clinic or individual practice association?

5. Do any of the primary care physicians refuse or prefer not to care for children with disabilities?

6. Will the primary care provider assigned to a child be a pediatrician?

7. What is the procedure for changing the primary care physician?

8. Do the specialists affiliated with the HMO have training and experience in treating children?

9. What suppliers of durable medical equipment or orthotics does the HMO use? Are subscribers free to select any of these suppliers? Which suppliers have experience in serving children?

10. Are there restrictions on coverage of physical, occupational or speech therapy?

11. Are there restrictions on coverage of mental health services?

12. Are there restrictions on the length of time for which mental health services will be authorized?

13. What preventive services does the HMO offer and at what cost to subscribers?

14. What financial incentives (bonuses, penalties) are used to encourage physicians to control utilization and costs of services?

15. Will the HMO pay for a second opinion from a physician not affiliated with the HMO?

16. Does the HMO have an internal grievance procedure? If so, how does it work and who makes decisions on grievances?

17. Does the HMO exclude coverage of services that might be provided to children under a special education program? Are such services covered if the child is not eligible for a special education program?

18. Are mental health services available from providers with expertise in servicing children?

19. What does the HMO consider a reasonable distance to travel to see a provider? Will the HMO make referrals to out-of-plan providers if no HMO provider is geographically accessible?

20. Is the HMO financially solvent? (Your Insurance Commissioner's office may have this information about the financial status of the HMO).

III. General Health Care Information

1. Get information about your insurance policy, HMO contract or PPO contract in writing from your insurance company, HMO or PPO.

2. Always know your insurance agent or employee benefits representative and where he/she can be reached.

3. Know where the copy of your policy is located. Read through it carefully as soon as you receive it.

4. Know your policy number and enrollment code and include them with any inquiry.

5. Keep a record of all phone calls, include date, time, person and content of the conversation.

6. Make a clear and concise presentation of any information. Always speak to your child's medical needs and how long they are expected to last. Demonstrate how paying for a particular service or item will improve the outcome, i.e., how providing a service or item will make your child more independent.

Developed by Julie Beckett, National Maternal and Child Health Resource Center, University of Iowa.

MEDICAL INSURANCE SUMMARY

Family Member Name:_____ Year:_____

Invoice Date	Billed From Whom	Billed For What	Date of Visit	Amt. Of Bill	Date Paid	Date Mailed To Ins.	How Ins. Handled Charges	Amt. not Covered By Ins.
10/15	Dr. Jones	Off. Visit throat culture	10/12	$26.00	10/12	11/1	Paid 80% 11/20	$ 5.20
	Smith Pharmacy	Amoxicillin #123456	10/13	$ 9.69	10/13	11/1	Paid 80% 11/25	$ 1.94
10/15	Patient's Hospital	X-Rays	10/1	$45.00		They Sent	Paid 100% 11/31	-----
9/20	Dr. Green	Office Visit	9/3	$20.00	9/3	10/5	Applied To Ded.	$20.00

POINTERS FOR TRACKING INSURANCE

PEAK DEVELOPED THIS MEDICAL INSURANCE SUMMARY FORM TO HELP FAMILIES KEEP BETTER TRACK OF MEDICAL BILLS AND EXPENSES. SOME TIPS FOR COMPLETING IT ARE:

* USE A SEPARATE FORM FOR EACH FAMILY MEMBER.

* USE ENTRY #1 AS A SAMPLE DOCTOR'S VISIT ENTRY.

* USE ENTRY #2 AS A SAMPLE FOR RECORDING PRESCRIPTIONS.

* USE ENTRY #3 TO RECORD HOSPITAL CHARGES.
  Hospitals usually bill insurance companies directly themselves so you might not have to mail the bill to the insurance company. It's a good idea to keep a record anyway.

* USE ENTRY #4 IF YOUR DEDUCTIBLE ISN'T MET.
  An office visit (like entry #1), but in this case the insurance company didn't reimburse the family because they applied the amount against the deductible.

* AT THE END OF EACH YEAR, TO SEE HOW MUCH YOU ACTUALLY PAID OUT OF YOUR POCKET, ADD ALL THE FIGURES IN THE LAST COLUMN ON THE RIGHT. YOU CAN APPLY THESE EXPENSES AGAINST YOUR INCOME TAXES IN SOME CASES.

Note: From PEAK-Parent Education and Assistance for Kids (1986). 6055 Lehman Drive, Suite 101, Colorado Springs, CO 80918, (719) 531-9400 or 1-800-284-0251. Reprinted by permission.

RECOMMENDED PEDIATRIC BENEFITS

Children with special health care needs often require a wider scope and depth of benefits than is generally offered by many private and public health insurance plans. The following is a comprehensive list of pediatric benefits developed by the American Academy of Pediatrics (AAP) that can be used to compare with benefits offered in each of the plans you are considering. In practice, most health insurance plans do not offer the wide array of pediatric services recommended by the AAP nor do insurers necessarily use the same terms in their brochures as those listed below.

If you are not sure that a benefit is covered, call your insurance agent for information. If there is a benefit that your child will need and it is definitely not covered, you may attempt to obtain the benefit by negotiating with your employer or insurer with assistance from your child's physician. Even though a benefit is covered, limits can be imposed (for example, 14 mental health outpatient visits per year). Make note of such limits when comparing plans.

1) Medical care, including well child visits, and diagnosis and treatment of acute and chronic illness, developmental disabilities, learning disorders, and behavioral problems, as directed or prescribed by a physician.

2) Surgical care, including reconstructive procedures for birth defects.

3) Mental health services, as directed by a physician, including those appropriate for treatment of substance abuse and other psychosocial problems.

4) Emergency and trauma services.

5) Inpatient hospital services.

6) Specialty and subspecialty pediatric consultations occurring either in an inpatient or outpatient setting.

7) Family planning services.

8) Pregnancy services including:

   a. Prenatal care;
   b. Prenatal consultation with a pediatrician;
   c. Care of all complications;
   d. Termination of pregnancy; and
   e. Care for the pregnancy of a single dependent of the policy holder.

9) Care of all newborn infants including:

   a. Attendance at high-risk deliveries;
   b. Examination and health supervision from the time of birth; and
   c. Treatment of birth defects and other illnesses or injuries.

10) Laboratory and pathological services.

11) Diagnostic and therapeutic radiology services.

12) Anesthesia services.

13) Rehabilitative service and therapies delivered under the direction of a physician, including:

    a. Physical therapy;
    b. Speech therapy; and
    c. Occupational therapy.

14) Home health care and the services of a licensed private duty nurse, as directed by a physician.

15) Hospice care for the child who is terminally ill.

16) Respite care for the caregivers of the child with chronic illness or disability.

17) Long-term care services delivered in an intermediate care or skilled nursing facility in lieu of hospital care.

18) Case management and care coordination of the special medical and social services needed by children with special health care needs.

19) Medical and social services to evaluate and treat suspected child abuse or neglect, as directed by a physician, in both inpatient and outpatient settings.

20) Transfer/transport (ground or air) to the hospital or health facility, as directed by a physician.

21) Nutritional counseling and assessments, as performed, directed, or prescribed by a physician.

23) Prescription drugs, medical and surgical supplies, corrective eyeglasses or lenses, hearing aids, and special nutritional supplements.

24) Rental or purchase of durable medical equipment and prostheses/braces.

Note: From McManus, M.A. (1988). Understanding Your Health Insurance Options: A Guide for Families Who Have Children With Special Health Care Needs. Association for the Care of Children's Health, 3615 Wisconsin Ave., Washington, D.C. $2.75 plus $1.00 for shipping/handling.

MAKING A FINAL DECISION

The following steps need to be carefully considered before making a final decision on the best insurance plan for your family.

1) Determine, with your doctor's assistance, your family's likely needs for health care in the coming year.

2) Obtain copies of all the insurance brochures you are considering, including your present plan. Some employers also offer comparison charts of the plans they use.

3) Evaluate the enrollment requirements, costs, and benefits in each plan.

4) Estimate your projected annual costs for insurance and medical services. Don't forget to take into account the catastrophic protections offered.

5) Determine if your pediatrician is participating in the plan. If not, find out about your ability to see a personal physician, accessability to pediatric specialists, qualifications and experience of plan doctors, use of allied health professionals, location of services, and other concerns.

6) If you need assistance, ask your pediatrician or other primary health care provider, case manager, or employee benefits agent.

Note: From McManus, M.A. (1988). Understanding Your Health Insurance Options: A Guide for Families Who Have Children With Special Health Care Needs. Association for the Care of Children's Health, 3615 Wisconsin Ave., Washington, D.C. $2.75 plus $1.00 for shipping/handling.

Other questions parents may want to consider are:

1. Are services covered when medically prescribed or are many services subject to review?

2. Is prior authorization required for certain services? How is it obtained?

3. If I do not agree with the settlement of my claim, is there a process I can use to ask for a review? What is that process and how long does it take before I can expect a final resolution?

Note: From Seifert, A. Health Care Coverage. Golden Valley, MN: Courage Center. Sample publication.

MEDICAID

IF YOU HAVE A QUESTION ABOUT MEDICAID, CALL YOUR LOCAL DEPARTMENT OF HUMAN SERVICES OFFICE OR YOUR SOCIAL WORKER

Medicaid is a program which pays medical bills for low-income people who can't afford the costs of medical care. In Iowa, people receiving Supplemental Security Income (SSI) because of a disability are eligible to receive Medicaid. Individuals may also be eligible for Medicaid even if they are not receiving SSI.

Medicaid plans cover at least these basic medical services:

-- Inpatient hospital services (room and board, operating room fees, delivery room, X-ray, lab tests, medication given during hospital stay, etc.)

-- Outpatient hospital services (treatment, X-rays, tests, etc.)

-- Outpatient laboratory, X-ray services and rural health clinics

-- Skilled nursing services and home health care services for those 21 and over

-- Physicians' services (physicians' charges for office visits, care given in hospitals, treatment in hospital outpatient departments)

-- Family planning services

People can apply for Medicaid at the local Department of Human Services office. A form must be filled out by the individual or his parent. The information will be confidential. When applying, bring proof of:

-- Income level (pay stubs, other evidence of your income and that of relatives living with you, bankbooks, other evidence of savings or assets)

-- U.S. citizenship

-- Personal circumstances (age, unemployment, absence of one parent, etc.)

-- Disability (medical records, etc.)

Persons eligible for Medicaid receive a medical eligibility card every month.

Note: From Medicaid and You distributed by U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309 and Your Guide to Medicaid distributed by Iowa Department of Human Services, local County Offices.

Also available from the Iowa Department of Human Services are: Medicaid for SSI Related Persons and Medicaid for the Medically Needy.

MEDICARE

FOR INFORMATION ABOUT MEDICARE CONTACT YOUR LOCAL SOCIAL SECURITY OFFICE OR CALL 1-800-532-1440.

Medicare is a Federal health insurance program for people 65 or older, people of any age with permanent kidney failure, and individuals with disabilities who have been entitled to Social Security disability benefits for 24 months.

Medicare has two parts, 1) hospital insurance and 2) medical insurance. Hospital insurance helps pay for inpatient hospital care and certain follow-up care. Medical insurance helps pay for doctor's services and many other medical services and items.

Apply for Medicare at your local Social Security Office. The Office will also assist beneficiaries in filing claims and provide information about the program.

Note: From A Brief Explanation of Medicare, January 1986 edition. Distributed by U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309.

MEDICAID AND MEDICARE - WHAT'S THE DIFFERENCE?

MEDICAID **Assistance** Program

Medical bills are paid from federal, state and local tax funds.

It serves low-income people of EVERY AGE.

Patients USUALLY PAY NO PART of costs for covered medical expenses. A small co-payment is sometimes required.

A FEDERAL AND STATE program. It varies from state to state and is run by state governments within federal guidelines.

MEDICARE **Insurance** Program

Medical bills are paid from trust funds which those covered have paid into.

It SERVES PEOPLE OVER 65 primarily, whatever their income; AND serves SOME YOUNGER DISABLED PEOPLE and dialysis patients.

Patients PAY PART of costs through yearly deductibles for hospital and other costs. Small monthly premiums are required for non-hospital coverage.

A FEDERAL program, it's the same everywhere in the U.S. and is run by the federal government.

Some people are covered by both Medicare and Medicaid.

Medicaid pays their Medicare premiums and deductibles. It also pays those parts of medical expenses not covered by Medicare but included in the state's Medicaid program.

Note: From Medicaid and You, p. 12. Distributed by Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309.

MEDICAID AND THIRD PARTY REIMBURSEMENT SYSTEMS:

NEW MEDICAID LANGUAGE ENACTED

July 1, 1988 President Reagan signed into law P.L. 100-360, "The Medicare Catastrophic Coverage Act". Although the legislation related primarily to Medicare, it also contains a significant amendment to the Social Security Act which relates to the financing of services included in a child's Individualized Education Plan (IEP) or the Individual Family Service Plan (IFSP) of an infant or toddler (required in 1991 under the implementation of Part H, P.L. 99-457). According to the amendment, Medicaid reimbursement cannot be restricted or prohibited for covered services for a child with handicaps because the services are included in an IEP or an IFSP.

While state education agencies are financially responsible for educational services, in the case of Medicaid-eligible handicapped children, state Medicaid agencies could be responsible for "related services", such as speech pathology and audiology, psychological services, physical and occupational therapy, and medical counseling and services for diagnostic and evaluation purposes identified in the child's IEP if the are covered under the state's Medicaid plan.

This change in Medicaid legislation is expected to have significant impact on the collaboration of financing of services included in an IEP or IFSP.

For more information contact your Area Education Agency, Director of Special Education.

IOWA COMPREHENSIVE HEALTH ASSOCIATION

The Iowa Comprehensive Health Association (ICHA) provides health insurance to Iowa residents who are unable to find adequate coverage in the private market due to their mental or physical condition. ICHA is a health insurance "pool", created by the State Legislature and administered by Mutual of Omaha. All health insurance companies doing business in Iowa must contribute to the pool.

The policies offer a $500 or $1,000 deductible and a $250,000 maximum lifetime benefit. In order to qualify, an individual must have been rejected for private health insurance. There is a six month waiting period for any pre-existing condition. ICHA can be a Medicare supplement. There is a maternity option for an additional cost. The cost of health insurance through ICHA depends on the person's age and sex and coverage is available for individuals or families.

Iowa residents can apply through any agent licensed to sell health insurance in Iowa. Information can be obtained from your agent or from:

Iowa Comprehensive Health Association
Mutual of Omaha Insurance Company
P.O. Box 31746
Omaha, Nebraska 68131
1-800-445-8603

THE CARING FOUNDATION

The Caring Foundation is a program administered by Blue Cross and Blue Shield of Iowa. The purpose of the Program is to provide a health care insurance plan for children of low-income families who are not eligible for government health care programs (i.e. Medicaid, Medicare) and who cannot afford private health care insurance. The goal is to provide for primary and preventive care for children through their formative years to give them a healthier start in life. Eligibility requirements for The Caring Foundation are listed below:

1) Child (applicant) is an unmarried son or daughter, stepchild, legally adopted child, or a child for whom you or your living spouse are legally appointed guardian.

2) Child (applicant) must be a resident of the state of Iowa for a least the last six (6) months.

3) Child (applicant) must be between the ages of 0-19.

4) Child (applicant) must be a full-time student if age six or older.

5) Child (applicant) cannot be eligible for any public health care plan including Medicaid, Medicare or any other government-sponsored program.

6) Household income cannot exceed income level ranges for Federal Poverty Guidelines. (Example: Income for a family of four cannot exceed $12,100 per year).

7) All eligible children in family must apply.

For more information on eligibility or to apply, call 1-800-223-KIDS, or write to:

The Caring Foundation
Station 150
636 Grand Avenue
Des Moines, IA 50309

ARC SPONSORED INSURANCE PROGRAMS

FOR MEMBERS

Life Insurance
Group Life Insurance available to members of local chapters and spouses of up to $150,000.

Life Insurance for Persons With Mental Retardation
Life Insurance protection is made available to persons with mental retardation in amounts of $2,000, $5,000, $7,500, $10,000 at competitive rates. Coverage to age 70.

In-Hospital Dollars/Medicare Supplement
Provides up to $200 per day for persons with mental retardation when confined in hospital, regardless of other Plans in effect. Also includes special Medicare Supplement Benefit.

For additional information relative to Plans available to members, you may call toll free 1-800-621-9903. Illinois residents call 1-800-572-3801.

FOR MEMBER CHAPTERS: (Provided at no cost)

Fidelity Bond
Provided protection for loss due to dishonest act by officers, volunteers or employees of the chapter. The policy has a $100,000 limit. This coverage is provided to all chapters at no charge. Higher coverage available upon request.

Chapter Accident Insurance
For injuries sustained while participating or traveling directly to or from organized activities sponsored by the Chapter, include Bike Hikes, Walk-A-Thon, etc. Covers both persons with mental retardation and volunteers alike. Provides Accidental Death and Dismemberment up to $5,000 and Accident Medical Indemnity up to $25,000. This coverage is provided to all chapters at no charge.

FOR MEMBER CHAPTERS: (Optional Coverage)

Safety Group Program
Provides all risk protection for loss of real and personal property owned by the ARC Chapter, as well as liability protection for the Chapter itself, including libel, slander, employee and volunteer coverage, teachers liability. In addition, it can provide workers' compensation, automobile and umbrella coverage.

Directors and Officers Liability Coverage
Provides protection for directors, officers, trustees and the executive directors for losses they become legally obligated to pay by reason of a wrongful act, including legal costs. It is written with a limit of $1,000,000 (higher limits are available).

Professional Liability and Malpractice
Provided protection for the Chapter, as well as the directors, officers, trustees, employees and volunteers for any injuries to persons or damage to property caused by any director, officer, trustee, employee or volunteer while acting in a "professional" capacity. It is written with a limit of $1,000,000 (higher limits available).

For additional information relative to Plans available to Member Chapters, you may call 201-249-9100.

WHAT TO DO WHEN HEALTH INSURANCE WON'T PAY

No matter what type of health insurance plan you have, it makes good sense to be prepared early to defend your claim. Here's how to protect your rights when a dispute arises:

-- Once you're notified of a denial, check over all the paperwork for errors, including clerical and mathematical errors. A simple letter from you to your insurance company may clear these problems up quickly.

-- Have your doctor or nurse explain terms you don't understand.

-- Ask for your doctor's support. Many denials by insurance companies are impossible to contest without your doctor's active help.

-- If the problem involves medical interpretation, ask your doctor for a written explanation and send it to your plan administrator.

-- Take thorough notes about all phone calls or meetings.

-- Put your policy and claim numbers on all correspondence.

-- Keep copies of all correspondence and paperwork you send.

In most plans, experimental treatments and those not deemed "medically necessary", are commonly denied coverage. The problem is that both "medical necessity" and "experimental" are vague standards, subject to case-by-case interpretation by each insurance company.

To appeal when "medical necessity" is in question:

1. Ask your employer's benefits planner or your agent to explain your plan's definition of "medically necessary".

2. Ask your doctor why your treatment was based on medical necessity.

3. Have your agent or benefits planner help you contact plan officials.

4. If your claim is still denied, ask a lawyer about possible legal action.

If the insurer labels the treatment "experimental":

1. Ask your doctor to show why your treatment is no longer experimental.

2. Ask the maker of any breakthrough treatment device to help you prove that the device is not experimental.

Note: From Better Homes and Gardens (pp. 72-74) by P. Godwin, November, 1987, Des Moines, Iowa.

EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT (EPSDT)

OVERVIEW OF PROGRAM

EPSDT is designated by the Social Security Act. It is designed to provide funding, screening, diagnosis, and treatment to determine physical and mental disabilities. This program was created for providing early intervention medical care to children of low income families.

AGE REQUIREMENTS AND ELIGIBILITY

EPSDT services are available to those persons under the age of 21 and eligible for Medicaid. Parents must be informed about EPSDT services generally within 60 days following the date of a family or child becoming eligible for Medicaid services. If the family or child becomes ineligible for Medicaid and later becomes eligible, EPSDT services are available.

SERVICE(S)

Screening

The screening includes a medical history, complete physical examination, vision and hearing screening, dental inspection (individuals over age 3 must be referred for dental care), developmental assessment, and necessary lab tests and immunizations.

The screenings will be provided in a health care provider's office or at screening centers by the appropriate health care professional who is an approved Medicaid provider.

Diagnosis

If the screening indicated a need for further evaluation a referral for diagnosis is made and the child receives a complete diagnostic evaluation. Diagnosis may be a part of the screening and examination process.

Treatment

If treatment is needed it will be provided by a health care professional which may be a physician, screening center, or facility qualified to evaluate, diagnose and treat a child's health problem(s).

MANDATED SERVICES

Services are mandated to be offered to Medicaid clients but acceptance by the client is optional.

COST

There is no cost for EPSDT.

WHERE TO APPLY

Contact your local office of the Iowa Department of Human Services in the county in which you live.

RESPONSIBLE AGENCY

Iowa Department of Human Services

CONTACT SOURCE

Joe Mahrenholz, Supervisor
Non-Institutional Services and Utilization Review Section
Bureau of Medical Services
Iowa Department of Human Services
Hoover Office Bldg.
Des Moines, IA 50319

Note: From House-Deere, Deb, Southern Prairie Area Education Agency 15, Route 5, Box 55, Building 40-41, Industrial Airport, Ottumwa, Iowa 52501.

GLOSSARY OF HEALTH INSURANCE TERMS

Catastrophic Lifetime Maximum: The total dollar limit after which the insurer will no longer pay. Typically insurers offer a different lifetime maximum for mental health and substance abuse services.

Catastrophic Stop-Loss Protected Amount: The annual out-of-pocket expense limit after which the insurer will fully reimburse the costs of additional services.

Co-insurance: The percentage share of costs that you are expected to pay for covered services (i.e., 20/80 share).

Conversion and Continuation Policies: All employers (with more than 20 employees) sponsoring group plans must offer employees and their families the opportunity for temporary extension of coverage (called continuation coverage) at group rates where coverage would otherwise end due to death, termination of employment or reduction of hours, divorce or separation, eligibility for Medicare, loss of child's "dependent" status, regardless of any pre-existing condition. Continuation coverage may go on for three years unless coverage was lost due to job termination or reduction in hours. In these instances, coverage can continue for 18 months. You must pay all or part of the premium to stay in this continuation coverage. At the end of the 18-month or 3-year period, you must be allowed to enroll in an individual conversion health plan offered under the group plan. This is often referred to as the COBRA provision.

Co-payment: The dollar share of costs that you are expected to pay for covered services (e.g., $2.00 per prescription drug).

Deductible: The amount you have to pay each year before the insurance company reimburses you or the health provider. Some plans also have deductibles for specific services such as mental health care and substance abuse treatment. Under family plans, typically two family members must meet their deductible before the plan contributes.

Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT): The preventive child health component of Medicaid. EPSDT was originally designed to identify and diagnose physical and mental problems among Medicaid-eligible children under 21 and treat those regardless of the limits imposed under the state Medicaid plan on the type and amount of such care.

Group Insurance: Insurance obtained through an employer, union, or association. Typically the family pays only a portion of the premium.

Guaranteed Renewable: An assurance that the insurer will continue to renew your policy as long as the premium is paid on time.

Health Maintenance Organizations (HMOs): The HMO is a plan that employs its own doctors and hospitals to manage and provide medical care. Unlike the PPO which allows for "out-of-plan" use (with financial disincentives), families in an HMO must receive their care directly from the HMO, unless specifically exempted. Families generally pay small co-payments for selected services and no deductibles or co-insurance.

Individual Policies: Insurance plans that an individual or family can obtain directly from an insurance company. Evidence of insurability is generally required and pre-existing condition exclusions are common.

Individualized Case Management Programs: Flexible benefit programs offered by a growing number of insurers for high-cost insured individuals. The individual's care is then closely managed.

Medicaid: A federal and state funded program which provides health care financing for persons with low incomes and disabilities. Every state offers different eligibility criteria and benefits.

Medically Needy Program: A Medicaid program operating in all but 14 states that offers coverage to individuals whose incomes are above Medicaid's eligibility cut-off and whose high medical bills drop their incomes to the eligibility level.

Participating Providers: A physician who signs a contract with a traditional, PPO, or HMO plan and agrees to accept the plan's allowable charges.

Pre-existing Conditions: Prior health conditions for which medical advice for treatment was received or recommended by a physician which may or may not be covered by subsequent insurance policies.

Preferred Provider Organization (PPO): A group of physicians or hospitals who contract with an insurer or employer to manage and provide some or all of the health services covered under the insurance plan. Fiscal incentives are offered to families when the preferred providers are used. If the preferred providers are not used, families generally have to pay some portion (e.g., 20-30%) of the fee.

Premiums: The cost of the insurance plan.

Prior Authorization: Before services are rendered, approval from the insurance plan or a designated primary care physician must be obtained or the service will not be reimbursed.

Traditional Plan: A plan where you select your own physician and manage the payment of your medical bills. After the deductible has been met, you generally have to pay a portion of the full costs (e.g., 20%) up to a certain dollar amount and then the insurer fully pays.

RESOURCES AND REFERENCES

Health Care Coverage, Resources and Financing

A Brief Explanation of Medicare, (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293, Federal Building, 210 Walnut Street, Des Moines, Iowa 50309).

A Guide to Health Care Coverage for the Child with a Chronic Illness or Disability. (Available from Center for Public Representation, 520 University Ave., Madison, Wisconsin 53703).

> This guide is another source on insurance issues. The guide was prepared by Alice Leonard for the Community Based Maternal and Child Health Project of the Center for Public Representation in Madison, Wisconsin. Although the resources are for Wisconsin residents, most of the information is relevant for other states. Cost is $10.00

Association for Retarded Citizens of the United States Group Term Life Insurance Plan. (Available from Association for Retarded Citizens, Group Insurance Administrator, Association Consultants, Inc., 600 W. Fulton Street, Chicago, IL 60606.)

> Fact sheet highlighting the benefits and coverages of the group policy issued to the Association for Retarded Citizens of the United States through American Heritage Life Insurance Company.

Hager, Dr. William, Commissioner of Insurance for the State of Iowa, Iowa Insurance Division, Lucas Building, Des Moines, IA 50319. General Information: (515) 281-5705 Complaints/Inquiries: (515) 281-4241

> Contact the Commissioner of Insurance for the State of Iowa if you have an existing insurance policy for an individual with a disability and are having a problem with its administration or think that the policy is being mishandled. The Commissioner of Insurance can also be contacted to find out the financial condition of an insurance company or HMO.

Iowa Comprehensive Health Association, State Comprehensive Health Association. (Available from Administrator: Mutual of Omaha Insurance Company, P.O. Box 31746, Omaha, NE 68131 or phone 1-800-445-8603).

> This program is designed to provide health insurance to Iowa residents who are unable to find adequate health insurance coverage in the private market due to their mental or physical condition. The brochure describes the benefits, exclusions, eligibility and application procedures for the ICHA Program.

McManus, M.A. (1988). Understanding Your Health Insurance Options: A Guide for Families Who Have Children With Special Health Care Needs. Association for the Care of Children's Health, 3615 Wisconsin Ave., Washington, D.C.

> Explanation and comparison of private insurance, HMOs and PPOs. Worksheets and case study examples are provided to assist families in comparing and determining the best health care coverage that takes into account enrollment, cost and benefits factors. (Cost: $2.75 plus $1.00 shipping and handling per copy).

Medicaid and You, (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293, Federal Building, 210 Walnut Street, Des Moines, IA 50309).

Medicaid for Iowa ADC Recipients and ADC-Related Recipients, rev. (1989, July). (Available from Iowa Department of Human Services, local county offices).

> Highlights eligibility, program requirements, services available, application and payment procedures, and your responsibilities as a recipient of Medicaid in the ADC and ADC-related programs.

Medicaid for SSI Related Persons, rev. (1989, April). (Available from Iowa Department of Human Services, local county offices).

> Highlights eligibility, program requirements, services available, application and payment procedures, and your responsibilities as a recipient of Medicaid in the SSI related programs.

Medicaid for the Medically Needy, (1989, October). (Available from Iowa Department of Human Services, local county offices).

> Discusses eligibility, program requirements and procedures, and medical services available for the medically needy through the Medicaid program.

Medicaid Made Easy. (Purchase or order through your local bookstore or order directly from Addison-Wesley Publishers, 1-800-447-2226, Cost $10.95).

> Medicaid Made Easy is a guide that explains what Medicare does and does not cover, hospital discharge rights and how to negotiate doctor's fees, plus much more. The guide has an easy to understand approach on how to wade through the regulations surrounding Medicare.

National Maternal and Child Health Resource Center, (1989). College of Law Building, The University of Iowa, Melrose and Byington Streets, Iowa City, IA 52242.

> The Mission of the National Maternal and Child Health Resource Center is to promote the improvement of health and related services for mothers and children, including children with special health care needs. Their activities include: Information Clearinghouse; Research and Studies; Technical Assistance and Consultation; Education and Training; and Advocacy. Their projects include: Building Community-Based Systems of Services for Children with Special Health Care Needs and Their Families; Financing of Health and Other Services for Children With Special Health Care Needs; Family-Centered, Community-Based Case Management; Implementation of Part H of Public Law 99-457 (early intervention services for handicapped infants and toddlers); Family-Centered Care Project; and development of a Child Profile Reporting Form and Automated Management Information Systems.
>
> Julie Beckett, Associate Director of Consumer Affairs, National Maternal and Child Health Resource Center, is willing to answer questions parents and others may have concerning health care financing for the disabled. Contact her at the above address.

Your Guide to Medicaid, rev. (1988, November). (Available from Iowa Department of Human Services, local county offices).

A guide to the types of services and supplies available through Medicaid.

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SPECIALIZED LIVING ARRANGEMENT

Note: In some settings this program is called "Community Supervised Apartment Living Arrangement Services - CSALAS"

Goal

To enable adults with disabilities requiring minimal to extensive supervision, training and support, to live in the community.

Types of Person Served

Persons with mental, developmental, physical or other disabilities.

Admission Criteria

Clients must generally be age 18 or older and cannot be harmful to self or others. There must be evidence of potential to benefit from the program, and the client must be able to meet room, board and personal expenses.

Services Provided

Basic services include: live-in or monitoring supervision; assistance with personal and social adjustment; training in self-help and community living skills; and individual program coordination.

Optional services can include: transportation; recreation and leisure services; adult basic education; advocacy; and other enabling services as needed.

Program Length

Program length is based on client progress, and is not time limited.

Disciplines/Staff Involved

The staff includes: residence managers; case managers; and other professionals as needed.

Expected Results

Clients can expect to maintain or improve independent functioning and maintain or increase integration into the community. Some clients will move to less restrictive settings.

Facility Size

The residential setting may range from independent living (one's own residence) to having live-in services available in a building specifically for this program.

RESIDENTIA

Program Title(s)

Residential Care Facility for the Ment

Residential Care Facility for the Chro

Residential Care Facility (RCF)

Goal

To provide assessment, supervision an with mental retardation, mental illness, or otl their physical and social self-sufficiency and i

Types of Person Served

Persons with mental, developmental,

Admission Criteria

Clients must be age 16 or older. Ther requires no more than personal care and sup examination within one year is required prior scheduled vocational training program, activi

Services Provided

Basic services provided include: 24-h social and community awareness; and leisure supervision, management; individual progran

Optional services can include: Psycho transportation; pre-vocational services; nursi education.

Program Length

Program length is based on client pro

Disciplines/Staff Involved

The staff includes: residential living s professionals as needed.

Expected Results

The client may expect to maintain or i increase integration into the community. So

Facility Size

RESIDENTIAL CARE FACILITY

y for the Mentally Retarded (RCF/MR)

y for the Chronically Mentally Ill (RCF/MI)

y (RCF)

supervision and training in a residential setting to enable adults
l illness, or others needing similar services, to maintain or improve
fficiency and independence.

velopmental, physical or other disabilities.

or older. There must be physicians certification that the person
l care and supervision, does not require nursing care. A physical
required prior to admission. The client must be enrolled in a
rogram, activity program or employed (RCF/MR only).

include: 24-hour supervision; training in self-care; housekeeping;
ss; and leisure skills; recreation activities; food services; medication
vidual program coordination; and counseling.

clude: Psychological, speech, physical and occupational therapy;
services; nursing services; dietary services; and adult basic

on client progress. There is no time limit.

dential living staff; activity coordinator (16 beds or more); other

o maintain or improve independent living skills, and maintain or
mmunity. Some residents will move to more independent settings.

Residential setting may range from a small (6-8 bed) group home to a large (50+ bed) campus setting.

INTERMEDIATE CARE FACILITY (ICF)

Program Title(s)

Intermediate Care Facility for the Mentally Retarded (ICF/MR)

Intermediate Care Facility (ICF)

Goal

To provide assessment, treatment and habilitation of persons with mental retardation or others needing similar care in a residential setting to help each individual reach his or her maximum level of functioning.

Types of Persons Served

Persons with mental, developmental, physical or other disabilities.

Admission Criteria

There are no age limitations. There must be a prior diagnosis and evaluation, and the need for ICF care must be certified by DHS (Iowa Foundation for Medical Care).

Services Provided

Basic services offered include: 24-hour care and supervision; training in self-help; community living skills; social skills; recreation activities; individual program coordination; behavior management; nursing; medical; dental services; dietary and food services; speech therapy; audiology; psychological services; transportation; pharmacy services; physical therapy; occupational therapy; social services.

Optional services can include: pre-vocational training; psychiatric services; adult basic education.

Program Length

Program length is based on client progress, there is no time limit.

Disciplines/Staff Involved

The staff includes: residential living staff; Qualified Mental Retardation Professional (QMRP) supervisors, nurses, aides; activity coordinators; physicians; dentists; dieticians; physical therapists; occupational therapists; social workers; speech therapists; psychologists; other professionals as needed.

Expected Results

Clients may expect to maintain or improve basic living skills, and maintain or increase integration into the community. Some residents will move to less intensive levels of care.

Facility Size

Residential setting may range from a small (6-8 bed) group home to a large (50+ bed) campus setting.

GROUP FOSTER CARE - COMMUNITY MR/DD

Goal

To provide residential care, training and specialty services to enable children with disabilities to remain in the community and to prepare them for the highest possible level of independent living.

Types of Persons Served

Children with mental, developmental, physical or other disabilities to age 18, or to age 21 if in school.

Admission Criteria

The client must be involved in a regular day program Monday through Friday. He/she must also need varying degrees of supervision and/or training greater than can be provided in the natural or foster home.

Services Provided

Basic services provided include: supervision and training in self-care; domestic skills; individual program coordination; client/family counseling; and social work.

Optional services can include: nursing; occupational, physical, speech, music and behavior therapy; psychological services; transportation; and health care.

Program Length

Program length is variable and the client may remain until the age limit is reached.

Disciplines/Staff Involved

The staff includes: instructional staff; residential living staff; and other professionals as needed.

Expected Results

Some clients may expect to return home, other clients may move to ICF/MR, RCF/MR, or a Specialized Living Arrangement. Clients may expect to maintain or improve daily living skills and integration in the community.

Facility Size

Residential setting may range from a small (6-8 bed) group home to a large (50+ bed) campus setting.

GROUP FOSTER CARE - COMPREHENSIVE MR/DD

Goal

To provide residential care, training and specialty services to enable children with disabilities and who require varying degrees of supervision to remain in the community and to prepare them for the highest possible level of independent living.

Types of Persons Served

Children with mental, developmental, physical or other disabilities to age 18, or to age 21 if in school.

Admission Criteria

The client must be involved in a regular day program Monday through Friday. He/she must also need varying degrees of supervision and/or training greater than can be provided in the natural or foster home or in Community Group Foster Care.

Services Provided

Basic services provided include: supervision and training in self-care; domestic skills; individual program coordination; client/family counseling; social work; and intensive behavior services.

Optional services can include: nursing; occupational, physical, speech, music and behavior therapy; psychological services; transportation; and health care.

Program Length

Program length is variable and the client may remain until the age limit is reached.

Disciplines/Staff Involved

The staff includes: instructional staff; residential living staff; and other professionals as needed.

Expected Results

Some clients may expect to return home, other clients may move to ICF/MR, RCF/MR, Specialized Living Arrangement or Community Group Foster Care. Clients may expect to maintain or improve daily living skills and integration in the community.

Facility Size

Residential setting may range from a small (6-8 bed) group home to a large (50+ bed) campus setting.

RESPITE CARE

Goal

To provide short-term residential care, in or out of the home, for temporary client and/or family relief from stress and ongoing supervisory responsibilities or to accommodate unexpected family situations.

Types of Person Served

Persons with mental, developmental, physical or other disabilities, and their families.

Admission Criteria

There must be a documented disability.

Services Provided

Basic services provided include: residential care and supervision; and recreational activities.

Optional services can include: nursing services; transportation; and other enabling services as needed.

Program Length

Program length is variable.

Disciplines/Staff Involved

The staff includes: residential living staff; and other professionals as needed.

Expected Results

Respite Care will enable individuals to return to care of natural or foster parents.

Note: Taken from Iowa Facilities Management Information System Program Definitions, Michael Crawford, Iowa Association of Rehabilitation and Residential Facilities, 913 9th St., Suite 3, West Des Moines, Iowa 50265. Reprinted by permission.

ADDITIONAL RESIDENTIAL SERVICE OPTIONS

Apartment Follow-Along

This service is provided by case managers or advocates, who monitor and assist clients living in their homes, apartments or condos. Guidance is available for shopping, recreation, nutrition, etc. The amount of contact depends on client's personal needs.

Living Support and Training

A program of support for persons with mild-severe disabilities, who live alone or with a roommate in a home, apartment or condo. Persons receive 2 to 10 hours training and support. They also have Individual Program Plans (I.P.P.).

Attendent Care

Apartment living with attendent or advocate as roommate.

Natural/Adoptive Home or Friend's Home

Person lives with relatives (usually family and/or parents), friend or friend of family. S.S.I. money may help with room and board.

Foster Care - Specialized Adult

Family-type care with limit to three persons in home of married couple. Social worker is available to assist foster parents and son or daughter. Some prerequisite skills are required.

Skilled Nursing Facilities

Privately owned, 24-hour medical/nursing care funded by Department of Health. Offers day care services and limited evening activities to residents. Special events are also provided.

Institution

24-hour residential facility for children and adults, state owned and operated. Major services include: behavior problems; complicated medical or dental needs; seizure treatment and diagnosis; and emergency/high risk clients. May provide day care services.

Note: Taken from NEW HATS, INC., P.O. Box 57567, Salt Lake City, Utah, (801) 259-6613. Reprinted by permission.

IOWA'S TITLE 19 HOME-AND COMMUNITY-BASED SERVICES (HCBS) or MODEL WAIVER PROGRAM

By Denny Hoyt

Purpose: The HCBS Program reduces the need for institutional placements by making resources available in a person's own home and community. Clients receive Medicaid coverage for basic health care services plus additional waiver services such as homemaker, respite or personal care to promote self-care and/or family care. The HCBS Program is for people who otherwise must enter or remain in institutions to qualify for Medicaid because they do not meet financial guidelines for Supplemental Security Income (SSI) or other programs that provide Medicaid coverage. The Iowa Department of Human Services (DHS) administers the HCBS Program. Child Health Specialty Clinics (CHSC) has an agreement with DHS to assist with this program.

How to Find Out If Your Child Qualifies for Home-and Community-Based Services

First, contact your county Department of Human Services (DHS) for a medical assistance application. (Look under the governmental section in your telephone book.) Complete and return this form promptly. Fill the form out as if your child (who needs the services) is answering the questions. Names are placed on a list based, usually, on the date when a local DHS worker stamps the completed form. If retroactive (up to 90 days) Title 19 assistance is needed for past medical bills, you should request this at the time of application.

Second, unless you've done so already, apply to Social Security for Supplemental Security Income (SSI). To qualify for HCBS, a child must be denied SSI due to parental income and resources. Obtain the SSI denial in writing (should be obtained within past 6 months) and send it immediately to DHS. DHS will also check to see if your child qualifies for Medicaid under other programs.

Third, your child may not have more than $2000 of individual resources or more than $1104 in monthly income. Ask the DHS worker for suggestions if your child's individual resources and/or income are currently above the limits. There may be ways to satisfy these requirements.

Fourth, your child must be determined blind or disabled. DHS will make this determination unless Social Security recently did so and your child's condition has not changed.

Fifth, the Iowa Foundation for Medical Care (IFMC), a private agency contracted by DHS, must certify your child for an institutional level of care. From highest to lowest in terms of costs, these levels are (a) intermediate care facility for persons with mental retardation (ICF-MR), (b) skilled nursing facility (SNF), and (c) intermediate care facility (ICF). IFMC will review the physician's recent medical summary and information from various agencies describing your child and the appropriateness of the family home as a health care setting. DHS and CHSC, with your permission and assistance, will submit this information to IFMC. IFMC's decision is the most important factor affecting the amount of services, if any, a person may receive. This decision can be appealed, beginning with a letter to IFMC.

Sixth, DHS and, for children, also the CHSC Iowa Home Care Monitoring Program must determine that waiver services are necessary and available. For a service plan to be approved, at least one waiver service must be listed, the service(s) must be available or attempts being made to locate service(s), and the plan must be signed by your child's physician.

Seventh, DHS must evaluate the cost-effectiveness of providing waiver services. These services may not cost more than institutional care at the level approved by IFMC. Cost limits for all waiver services vary from $900 to $3000 monthly. There are also monthly limits for each waiver service and guidelines for who may provide each service.

Finally, DHS must confirm an opening exists in the HCBS Program. When the 200 maximum number is reached, applicants will be turned down and their names will be placed on a waiting list and reviewed, as openings occur, based on their order on the list.

Even if a client is within the 200 maximum, it may still take the state about 60-180 days to determine that a person qualifies for the HCBS Program. Medical payments (other than for waiver services), however, may be approved for up to 90 days before the application month, provided your child could have qualified for HCBS during that period. Once services begin, clients are reviewed at least every six months for level of care and continuing need for services. Income eligibility will be reviewed every 12 months.

Q. Is this Program Only for "High Tech Kids?"

A. No. Any child, adult, or elderly person may be eligible. Life-threatening health conditions and use of technology for life support are not requirements. Candidates may be at risk of institutionalization or may be leaving a hospital, state hospital school, nursing facility, intermediate care facility, intermediate care facility for persons with mental retardation, or less often, a residential care facility.

Q. How Can I Know If My Child Qualifies?

A. The only way to know for sure is to apply. Most importantly, the family must want the child at home and must have the skills needed to make home care effective. If that is true, your child will qualify if health and social service professionals can document seven facts: Your child (1) is blind or disabled, (2) needs care normally provided in medical institutions, (3) has individual resources of no more than $2000 and an income no greater than $1104 monthly, and (4) is otherwise ineligible for Medicaid because of parents' income and resources. Also, waiver services must be (5) necessary, (6) available, and (7) cost-effective when compared to institutional care.

Q. Is There an Opening Right Now?

A. Probably. The number of people who can be served at one time has increased from 50 to 200. Even if the 200 slots are presently filled, individuals do go off the HCBS program. Thus, it is <u>very important</u> that you complete and return as soon as possible an application to DHS so your child's name can be placed on the waiting list. Also go ahead and do step 2, which is to apply for SSI.

Q. What Services May HCBS Clients Receive?

A. Clients may receive (1) required services mandated under Title 19 for all Medicaid recipients; (2) optional services described in a state plan submitted by DHS and approved by the Secretary of Health and Human Services (HHS) in Washington, D.C.; and (3) waiver services requested by the state and approved by the Secretary of HHS. Required and optional services are provided to all Iowans receiving Medicaid. Only clients of the HCBS Program may receive waiver services.

Required services include patient and outpatient hospital services; physician services; laboratory and x-ray services; early periodic screening, diagnosis and treatment (EPSDT) services for individuals under age 21; rural health clinic services; and other services. Iowa also mandates payment for some transportation costs if necessary medical care is not available in the client's community, as well as diapers for clients age 5 and above.

Optional services include the services of dentists, optometrists, speech therapists, occupational therapists and physical therapists; prescribed drugs and certain medical equipment; and other services.

Waiver services are:

- **Respite Care**: Temporary care to relieve those who provide much of the person's care at home (e.g., parents, spouse).

- **Personal Care**: Assistance with activities of daily life (e.g. bathing, dressing, taking medication).

- **Homemaker**: Assistance with household duties (e.g., shopping, cleaning, cooking, bookkeeping, transportation).

- **Residential Services**: Habilitation, rehabilitation, and other services to improve skills for self-care and independent living.

- **Adult Day Care**: Activities provided through a program offered at an adult day care center.

Q. **How Are These Services Coordinated?**

A. Each client has a service coordinator (i.e., case manager) who is responsible for understanding guidelines for the HCBS program. This person works with the family to develop and carry out a plan for managing resources from a variety of people and agencies.

The service coordinator helps the family with several important tasks: (1) identifying needs and ways the family can meet its needs; (2) gaining knowledge about resources and service options; (3) arranging with agencies to make their resources available; (4) monitoring to see if services are meeting needs in a timely and effective manner; and (5) revising the overall plan to address problems, concerns, and changing needs. Service coordination is provided by DHS and, for children, also CHSC Iowa Home Care Monitoring Program.

Q. **Does The HCBS Program Make Private Insurance Unnecessary?**

A. No. Private insurance sometimes pays for needed services not covered by Medicaid. If you call your insurance company, ask about guidelines for in-home health care. (Registered nurse only? Maximum hours or visits? Copayments?) The Iowa Home Care Monitoring Program can help with questions about private insurance. Write or call: Iowa Home Care Monitoring Program, 246 University Hospital School, University of Iowa, Iowa City, IA 52242; (319) 353-6172. Insurance complaints should be directed to: Insurance Commissioner, Iowa Insurance Division, Lucas Building, Des Moines, IA 50319; (515)281-4241.

For more information, contact your county DHS office or the Iowa Home Care Monitoring Program. The Home- and Community-Based Services Program is explained in Chapter 83, Iowa Administrative Code, and Chapters VIII-D(1) and XIII-K, DHS Employee's Manual. You may request copies if you wish. Also ask for "Your Guide To Medicaid".

Why It's Called a Waiver Program

Medicaid is a health care financing program funded jointly by federal, state, and county governments under Title 19 of the Social Security Act. Until recently, federal regulations limited Medicaid to low-income people who are also aged, blind, disabled, members of families with dependent children, or first-time pregnant women. Also, the regulations allowed individuals only those services equally available to other Medicaid recipients.

Thus, in order to extend Medicaid eligibility to additional people and to expand the range of services available to those individuals beyond what is available to all Medicaid recipients, the federal government must waive (i.e., not enforce) certain Title 19 regulations.

That is what happened in 1981 after the parents of Katie Beckett, a Cedar Rapids girl hospitalized for three years, appealed to Congressman Tom Tauke for help in bringing their daughter home. Certain Title 19 regulations were waived to make Katie eligible for Medicaid even after leaving the hospital and to provide additional - waiver - services necessary to support her safely at home. Subsequently, the federal government in 1982 created the Model 2176 Waiver. This Medicaid option is available to all the states by request. Eligibility criteria and benefits vary from state to state. Iowa first requested a Model 2176 Waiver in 1984 and entitled it the Home- and Community-Based Services Program.

Author's Note

Special thanks to Kathi Kellen, Home and Community Services, Iowa Department of Human Services; Brenda Moore, Iowa Home Care Monitoring Program; and Julie Beckett, National Maternal and Child Health Resource Center, for reviewing this article before publication.

Note: Revised and reprinted by permission from the author and Iowa Exceptional Parent Center, "Unraveling a Medicaid Mystery," Parent Center Quarterly, Winter 1988-1989.

FAMILY SUPPORT SUBSIDY PROGRAM

OVERVIEW OF PROGRAM

The Family Support Subsidy Program is a new program which became effective on July 1, 1988. It was designed to help families financially to help meet the costs of caring of a handicapped child at home. There is a limited number of families which can be served on this program.

AGE REQUIREMENTS AND ELIGIBILITY

To qualify a child must:

1) Require special education services and be weighted 2.4 or 3.6 (not in regular classroom).
2) Be residing in or being considered for placement in a state hospital-school, mental health institute, community-based Intermediate Care Facility/Mentally Retarded (ICF/MR), foster group care facility, or foster family care.
3) Be a resident of Iowa.

The family net taxable income must be $40,000 or less.

SERVICE(S)

This program provides monthly cash payments that the family can use to pay for services. Some services that families use the payment for are: respite care, day care, attendant care, homemaker services, home intervention, home health care, recreation and alternative activities, purchase of medical or orthopedic equipment, home remodeling, individual or family counseling, family training or education, transportation, physical, occupational or speech therapy and insurance.

COST

There is no cost to families who qualify.

WHERE TO APPLY

Contact your local office of the Iowa Department of Human Services in the county in which you live. Ask for the Supervisor of the Family and Children's Service Unit.

RESPONSIBLE AGENCY

Department of Human Services.

CONTACT SOURCE

Division of Mental Health, Mental Retardation and Developmental Disabilities
Department of Human Services
Hoover State Office Bldg.
Des Moines, IA 50319

Or call (515) 281-5874 and ask for the Supervisor for Family Support Subsidy Program.

Note: From House-Deere, Deb, Southern Prairie Area Education Agency 15, Route 5, Box 55, Building 40-41, Industrial Airport, Ottumwa, Iowa 52501. Reprinted by permission.

COMMUNITY LIVING FOUNDATION FOR IOWANS WITH DEVELOPMENTAL DISABILITIES

OVERVIEW OF PROGRAM

The Community Living Foundation is a private non-profit organization whose goal is to provide family support services aimed at preventing inappropriate out of home placements.

AGE REQUIREMENTS AND ELIGIBILITY

Anyone who is diagnosed as developmentally disabled before the age of 22 is eligible for services. A developmental disability means the disability occurred before the age of 22.

SERVICE(S)

Support services may include financial assistance with the purchase of assistive devices and home modifications. Respite care, transportation, and homemaker services may be funded on a short term basis only. The services are provided to the person while they are in their own home.

When the funding is needed, the family member or person with a disability needs to call or write to the Foundation to request an application. If funding is granted, the Foundation then pays for all or part of the cost of the equipment or service. It is up to the family or individual to obtain the medical supplier, respite care giver, or whoever is needed to provide the equipment or services. The Community Foundation then works out the arrangement for payment with the supplier.

COST

There is no cost to the family for any service provided by the Community Living Foundation.

WHERE TO APPLY

Chris Morton
Community Living Foundation
2402 Forest Avenue
Des Moines, IA 50311
(515) 277-1903 or 1-800-722-0169

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SUNNYSIDE RESPITE SERVICES

OVERVIEW OF PROGRAM

Sunnyside Weekend and Week-Long Respite Services are designed to provide families caring for a disabled member at home an occasional break while the disabled person has a fun time at camp. Emergency respite care is also a part of the respite services provided by the Easter Seal Society of Iowa, Inc.

AGE REQUIREMENTS AND ELIGIBILITY

Respite Care Weekends and Emergency Respite services are available to any child three years of age and up with a physical or developmental disability, living at home, and not exhibiting severe emotional or behavior disorders. Emergency Respite Care - an emergency for sudden, unforeseen occurrences requiring immediate action, such as unexpected hospitalization of the care giver, or imminent danger of child abuse. Sunnyside personnel determine whether each situation qualifies for emergency respite, so that limited resources are used where most needed.

SERVICE(S)

Respite Care Weekends - seventeen (17) weekends per year are provided beginning on Friday at 6:30 p.m. and ending at 4:30 on Sunday.

Week-long Respites - provided during the months of January and/or March beginning at 1:30 p.m. on Sunday until 11:00 a.m. on the following Saturday.

Emergency Respite Care - provided around the clock and through the weekends for up to two weeks. The respite coordinator must be contacted during office hours (Monday-Friday, 8:30-4:30) to apply for services.

Qualified staff provide the services and care with sensitivity to the physical, social, and emotional needs of each child.

COST

Weekend Respite fees are $60.00
Week-Long Winter Respite fees are $180.00
Emergency Respite fees are $30.00 per day

The Easter Seal Society asks families to pay whatever part of the fee they can as long as other funding is available, but no one will be turned away because of the inability to pay. The services cost $103 a day and are supported by grants and donations as well as client fees.

WHERE TO APPLY

Respite Services
Camp Sunnyside
P.O. Box 4002
Des Moines, IA 50333
(515) 289-1933

CONTACT SOURCE

Jack Denniston, Recreation Director
Easter Seal Society of Iowa, Inc.
P.O. Box 4002
Des Moines, IA 50333
(515) 289-1933

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CAMP SUNNYSIDE

OVERVIEW OF PROGRAM

Sunnyside's Residential Camp is designed for children age 6 and older, adults, and senior citizens who have a disability. The program provides recreation and camping opportunities at its 130 acre site near Des Moines, Iowa.

AGE REQUIREMENTS AND ELIGIBILITY

Residential Camp is available to residents of Iowa age 6 and up that have a physical or developmental disability and not exhibiting severe emotional or behavioral disorders.

SERVICE(S)

Week long summer sessions beginning in early June. Camps check-in on Sunday afternoons and check-out Friday afternoons.

COST

One week sessions (5-day) cost $300.00. Camp Sunnyside asks participants or their families to pay whatever part of the fee they can, but they do not turn people away because of the inability to pay.

WHERE TO APPLY

Camp Sunnyside
Box 4002
Des Moines, IA 50333

CONTACT SOURCE

Pete Theismann, Director of Camping and Recreation
Camp Sunnyside
Box 4002
Des Moines, IA 50333

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SUNNYSIDE ADVENTURE CAMP

OVERVIEW OF PROGRAM

Adventure Camp offers the opportunity for a more rugged camping experience at scenic areas in Iowa. The program includes: A canoe trip, fishings trips, and travel camps.

AGE REQUIREMENTS AND ELIGIBILITY

Adventure Camp is available to residents of Iowa age 14 on up who have a physical or developmental disability. They must be physically independent (manual wheelchair or ambulatory), provide most of their own personal care, and have an active interest in going on a trip away from Camp Sunnyside.

SERVICE(S)

The Adventure Canoe Trip is a 12-day program. Campers check-in at camp on a Sunday afternoon. They spend several days preparing for the trip at Camp Sunnyside. They then spend about 8 days canoeing down a river, camping out, swimming, and fishing. They check out of camp on a Friday morning.

The Travel and Fish Camps are five-day sessions that start on Sunday afternoon and end on Friday afternoon. Campers spend four days and nights away from Camp Sunnyside visiting sites, fishing, and swimming.

COST

One week sessions (5-days) cost $300.00. The twelve-day canoe trip costs $500.00. Camp Sunnyside asks participants or their families to pay whatever part of the fee they can, but they do not turn people away because of the inability to pay.

WHERE TO APPLY

Camp Sunnyside
Box 4002
Des Moines, IA 50333
(515) 289-1933

CONTACT SOURCE

Pete Theismann, Director of Camping and Recreation
Camp Sunnyside
Box 4002
Des Moines, IA 50333
(515) 289-1933

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CAMP COURAGEOUS OF IOWA - RESPITE CARE

OVERVIEW OF PROGRAM

The Respite Care Program at Camp Courageous of Iowa provides a weekend full of fun and adventure for any physically or mentally disabled person, while providing a much needed break for the parent, care giver or family.

Emergency Respite Care is provided in the event of death, serious illness or extreme emotional trauma of the primary care giver.

AGE REQUIREMENTS AND ELIGIBILITY

Respite Care is open to any physically or mentally disabled individual who is living at home. There are no age restrictions.

SERVICE(S)

Respite weekends are scheduled throughout the year with activities which may include:

Swimming
Pony rides
Sensory awareness
Sledding
Gym activities
and much more

Emergency respite care is available 24 hours a day, 7 days a week, 365 days a year.

Medical Professionals provide everything from medication disbursements to treatments and therapy.

COST

Families of campers are asked to pay what they can, but no one is ever turned away for lack of funds.

WHERE TO APPLY

Jeanne Muellerleile, CCD
Camp Director
P.O. Box 455
Monticello, IA 52310-0455

CONTACT SOURCE

Charlie Becker, Executive Director
Camp Courageous of Iowa
R.R.#2, P.O. Box 455
Monticello, IA 52310-0455
(319) 465-5916

Note: From House-Deere, Deb, Southern Prairie Area Education Agency 15, Route 5, Box 55, Building 40-41, Industrial Airport, Ottumwa, Iowa 52501. Reprinted by permission.

RESOURCES AND REFERENCES

Residential and Community-Based Services

Camp Courageous of Iowa - Respite Care. For more information contact Charlie Becker, Executive Director, Camp Courageous of Iowa, R.R. #2, P.O. Box 455, Monticello, IA 52310-0455.

Camp Sunnyside. For more information contact Pete Theismann, Director of Camping and Recreation, Camp Sunnyside, P.O. Box 4002, Des Moines, IA 50333.

Community Living Foundation for Iowans With Developmental Disabilities. For more information contact Chris Morton, Community Living Foundation, 2402 Forest Avenue, Des Moines, IA 50311.

Early and Periodic Screening, Diagnosis and Treatment (EPSDT). For more information contact Joe Mahrenholz, Supervisor, Non-Institutional Services and Utilization Review Section, Bureau of Medical Services, Iowa Department of Human Services, Hoover State Office Building, Des Moines, IA 50319.

Family Support Subsidy Program. For more information contact Division of MH/MR/DD, Department of Human Services, Hoover State Office Building, Des Moines, IA 50319.

Iowa Association for Retarded Citizens. For more information contact Mary Etta Lane or Esther Fields, ARC/Iowa, 715 East Locust, Des Moines, IA 50309. 1-800-362-2927 or (515) 283-2358.

Iowa Association of Rehabilitation and Residential Facilities, Iowa Facilities Management Information System Program Definitions. Michael Crawford, Iowa Association of Rehabilitation and Residential Facilities, 913 9th St., Suite 3, West Des Moines, Iowa 50265.

Iowa Child and Adolescent Service System Program (CASSP). For more information contact Iowa Child and Adolescent Service System Program, Division of MH/MR/DD, Iowa Department of Human Services, 5th Floor, Hoover Building, Des Moines, IA 50319. (515) 281-8061.

Iowa Directory of Services for Persons With Developmental Disabilities. Available from the Iowa University Affiliated Facility, Division of Developmental Disabilities, University of Iowa Hospital School, University of Iowa, Iowa City, IA 52242

> Every two years, the Governor's Planning Council for Developmental Disabilities and the Iowa University Affiliated Facility publish a directory of services to assist in locating appropriate resources to provide for the needs of the developmentally disabled.

Muscular Dystrophy Association. For more information contact Muscular Dystrophy Association, 1000 73rd Street, Suite 15, Des Moines, IA 50311.

NEW HATS, INC., P.O. Box 57567, Salt Lake City, Utah, (801) 259-6613.

O'Leary, E.E. & Trotter, S.K., Transition Planning: Resource Directory of Services for Special Needs Populations, (Fall, 1989).

> The fourth edition of the Transition Planning: Resource Directory of Services for Special Needs Populations is a compilation of information and services obtained from agencies, organizations, and institutions throughout Area 11. The Directory is intended to be used as a reference for transition services and/or support identification. This publication is available through Heartland Area Education Agency 11, Newton Branch Office, 301 First St. S., Newton, IA 50208.

Sunnyside Adventure Camp. For more information contact Pete Theismann, Director of Camping and Recreation, Camp Sunnyside, P.O. Box 4002, Des Moines, IA 50333.

Sunnyside Respite Services. For more information contact Jack Denniston, Recreation Director, Easter Society of Iowa, Inc., P.O. Box 4002, Des Moines, IA 50333.

There's No Place Like Home [Film]. Produced by the Iowa University Affiliated Program. Available from The Clearinghouse at the Division of Developmental Disabilities, University Hospital School, Iowa City, IA 52242, 1-800-272-7713.

Section Six
SUPPLEMENTAL INCOME

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SUPPLEMENTAL SECURITY INCOME (SSI)

SSI is a Federal program operated by Social Security. The funding for the program is from income tax not Social Security taxes. The Social Security Administration administers the program, determines eligibility and makes the basic payments to recipients.

Individuals 65 or older may receive SSI. Additionally, if one is 18 or older and has a physical or mental disability which is expected to keep one from working for 12 months or longer, or the disability is expected to result in death, then an individual may be eligible for SSI. A child under 18 may receive SSI if the disability is as severe as one that would keep an adult from working, is expected to last at least 12 months, or may result in death. Qualifications for benefits to children may be made as early as the disability is diagnosed.

An adult or child who is blind may receive SSI if their vision is 20/200 or has a limited visual field of 20 degrees or less in the better eye with use of eyeglasses. Even if an individual's vision loss is not considered to be blindness, they still may be able to receive SSI.

Evidence of eligibility may include reports from doctors, other professionals, hospitals, clinics or institutions where the individual has been treated. Additional tests may be necessary and, if so, they are paid for by Social Security.

Being 65 or disabled or blind does not automatically mean an individual is eligible to receive SSI. Determination for eligibility is also dependent on the **resources** one owns and their **income.**

Resources

The term "resources" means things a persons owns. It includes real estate and personal property, such as household goods, savings and checking accounts, stocks and bonds, life insurance, certificates of deposit, Christmas Club accounts, cash, and other assets that can be applied to meeting a person's needs for food, clothing, or shelter.

Resource Limits

In 1989 the resource limits are $2,000 for one person and $3,000 for a couple. If under 18, not married and living at home, the parent's resources may be included with the child's if the parents' resources exceed $3,000 (or $2,000 if only one parent).

Resources That May be Excluded

Resources which may be excluded in determining the resource limit include: a) a home (principal place of residence); b) personal effects or household goods (total equity value is $2,000 or less); c) an automobile; d) life insurance policies (total face value of $1,500 or less); e) burial plots or spaces; f) burial funds (not to exceed $1,500); g) property used for self support; h) resources needed to achieve an approved plan for self support (vocational training, education, work related equipment can be part of an approved plan subject to approval by Social Security); and i) retroactive SSI payments or retroactive Social Security benefits are not counted as a resource for 6 months. An individual whose resources exceed the limit may still qualify by agreeing to sell the excess resources. Specific questions regarding resources or the disposal of excess resources should be made by calling your local Social Security office or by calling 1-800-234-5772.

Income

Income also effects eligibility and payments for SSI. Under SSI, "income" means anything a person receives that can be used to meet their needs for food, clothing or shelter. Income can also mean cash, checks, "in-kind" items such as food and shelter, savings accounts, stocks, bonds, spouse's income, and parental income (if the child is under 18 and not married). Income is divided into two categories under the SSI program - earned and unearned.

Earned Income

Earned income includes wages, net earnings from self-employment, earned income tax credit payments, and/or income received from sheltered workshops.

Unearned Income

Unearned income includes Social Security benefits, worker's or veteran's compensation, pensions, support and in-kind maintenance, annuities, rent and interest.

Items Not Considered Income

The following items are not considered income:

* Medical care and services (including reimbursements and payment of health insurance premiums by others)
* Social services (including reimbursements from programs)
* Receipts from the sale, exchange, or replacement of resources (such receipts are considered resources)
* Income tax refunds
* Payments by credit life or credit disability insurance (that is, insurance on charge accounts or other credit accounts)
* Proceeds of a loan
* Bills paid by someone else for things other than food, clothing or shelter
* Replacement of lost or stolen income
* Weatherization assistance

Income Excluded

The following income is excluded in determining SSI payment amounts:

* $20 a month of earned or unearned income (except some types of unearned income based on need, such as certain veterans' pensions)
* $65 a month of earned income plus one-half of earned income over $65 a month or, if there is no unearned income, $85 a month of earned income plus one-half of the remainder
* Government refunds of taxes paid on real property or on food purchases

* Amounts for tuition and fees paid from grants, scholarships, and fellowships
* Irregular or infrequent earned income totaling no more than $10 a month
* Irregular or infrequent unearned income totaling no more than $20 a month
* Foster care payments for a child who is not receiving SSI payments but has been placed in the recipient's household by an approved agency
* If a child, one-third of any child support payments received from the absent parent
* Earnings (up to $400 a month, but not more than $1,620 a year) of an unmarried blind or disabled child who is a student under 22
* If disabled or blind, the amount of income necessary for fulfillment of an approved plan to achieve self-support
* If blind, an amount equal to work expenses
* If disabled, an amount equal to impairment-related work expenses
* Food stamp assistance
* Housing assistance from Federal housing programs run by State and local subdivisions
* Benefits, compensation, or items from ACTION programs run by State and local subdivision
* Incentive allowances and certain types of reimbursement for individuals in certain training programs
* Grants or loans to undergraduate students from the Department of Education's educational programs
* Assistance furnished in connection with a Presidentially declared disaster and any interest earned on the assistance for the first 6 months
* Interest which is paid on excluded burial funds and left to accumulate
* Food, clothing, or shelter in a nonprofit retirement home or similar institution that is provided or paid for by a nonprofit organization which is not expressly obligated to do so
* Food, clothing, shelter, and home energy assistance provided in kind by a private nonprofit organization if the assistance is based on need and is certified by the State

For more information, write to the address below:

Note: From SSI, July 1988, SSA Publication No. 05-11000, ICN 480200 and A Guide to SSI for Groups and Organizations, January, 1989, SSA Publication No. 05-11015, ICN 480300. Available from U.S. Department of Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309.

SSI AND MEDICAID

SSI payments may continue for working disabled. As earnings increase, SSI will decrease or may stop because of countable income exceeding the Federal payment rate and any state supplement. If that were to occur, Medicaid coverage may be extended if one depends on it to work and earnings are not sufficient to pay for similar medical help. Medicaid may continue for working disabled or blind under 65 years of age if they:

* Continue to have a disabling condition
* Need Medicaid in order to work
* Are unable to afford equivalent medical coverage without assistance
* Meet all nondisability requirements for SSI payments (other than earnings)

(See previous section, Supplemental Security Income)

SSI AND PUBLIC INSTITUTIONS, PRIVATE INSTITUTIONS, MEDICAL INSTITUTIONS, AND GROUP HOMES

If one lives in a publicly operated community residence which serves no more than 16 people, they may receive SSI. Living in a public institution mainly to attend approved educational or job training that will help get a job also qualifies for SSI. If living in a public or private institution and Medicaid is paying for more than half the cost of care, SSI may still be received but at a reduced payment level. There are special rules that apply to recipients that enter a medical institution for a stay of less than 90 days. SSI payments may continue but only if Social Security is notified within 10 days following the month a person enters the medical institution.

Pre-Release Program

People about to be released from an institution can apply for supplemental security income (SSI) payments and get a decision before they are released. The rule, called a "pre-release program," has been in effect since 1978 and is designed to make it easier for eligible persons to move from an institution to the community. In addition, a recent change permits individuals in a pre-release program to file for food stamps at the same time they file for SSI.

The steps involved in setting up a pre-release arrangement are as follows:

* The Social Security office and the institution enter into a pre-release agreement to speed all pre-release activity.
* The Social Security office and the institution designate a liaison to handle the pre-release claim, including the application, identifying living arrangements, and securing the necessary medical and nonmedical evidence.

- The institution identifies the individual eligible for pre-release consideration.
- Social Security makes a decision on the SSI pre-release claim and notifies the institution of the results of claims processing. The local food stamp agency makes the decision on the food stamp application.

Social Security Information Items, July 1989 and August 1989. Social Security Administration, Office of Information, Room 4-J-10 West High Rise, 6401 Security Boulevard, Baltimore, Maryland 21235.

PLAN FOR ACHIEVING SELF-SUPPORT

A plan for achieving self-support can help an individual establish or maintain SSI eligibility and can also increase the individual's SSI payment amount. The plan allows a disabled or blind SSI recipient to set aside income or resources for a specified period of time for a work goal such as education, vocational training, or starting a business. The income and resources set aside will not count against SSI benefits for a reasonable time. This is generally 18 months and may go up to 48 months. The individual must have a feasible work goal, a specific savings/spending plan, and must provide for a clearly identifiable accounting of funds which are set aside. The plan must be in writing and have a specific time frame. The person is expected to follow the plan and to negotiate revisions as needed. Most people develop their plan with help from a vocational rehabilitation counselor, a social worker, or someone from Social Security. The Social Security Administration will evaluate the plan and determine its acceptability.

SSI AND WORK

Disabled or blind people who unexpectedly improve and are no longer considered disabled or blind may continue to receive SSI payments (and Social Security benefits) if they are participating in an approved State Vocational Rehabilitation program. This provision is intended to help disabled and blind people who unexpectedly improve and whose payments would otherwise end before they are prepared vocationally to return to work.

The SSI law encourages individuals who are disabled or blind to work. Once the individual meets the income and resource limits for eligibility, certain work related expenses can be deducted from earned income. Each deduction and amount must be approved by Social Security. Work related expenses generally allowed include:

Deductible Work Related Expenses

* Wheelchairs, respirators, braces, and other medical devices
* Attendant care services, such as assistance in going to and from work, a reader for the blind, or an interpreter for the deaf
* Transportation costs that are extraordinary, such as modifications to a vehicle
* One-handed typewriters, braille devices, telecommunications devices for the deaf, and certain other work-related equipment
* Regularly prescribed drugs and medical services needed to control an impairment
* Residential modifications, such as ramps or railings outside the home that might improve mobility
* Expendable medical supplies, cost of keeping a guide dog, and other miscellaneous expenses

Blind recipients are allowed deductions for certain work expenses in addition to those mentioned above. Examples are Federal, State, and Social Security taxes; routine transportation costs to and from work; and union dues.

NOTE: Earned Income Increase Rule Change for 1990

The amount that a disabled person can earn and still receive Social Security benefits has increased from $300 to $500 a month, under a new regulation proposed by Health and Human Services Secretary Louis Sullivan. The new figures, which set the standard for "substantial gainful activity: (SGA), will be effective January 1990.

The increase is expected to provide an additional incentive for the 5.2 million workers now receiving Social Security and supplemental security income (SSI) benefits to take significant steps toward work and economic independence.

The Social Security Act defines disability as the "inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months." The amount of earnings indicating substantial gainful activity is set by regulations issued by the Secretary of Health and Human Services.

The level of earnings affecting blind people is set by law and is currently $740 a month. This will not be affected by the proposed regulation.

The proposed regulation also affects the trial work period. Presently, if a disabled Social Security beneficiary returns to work and earns more than $75 in a month or exceeds 15 hours in self-employment, the individual enters a trial work period. Under the proposed regulation, the levels that trigger entry into the trial work period would rise to $200 of earnings in a month or 40 hours of self-employment.

If a disabled person begins to work, benefits continue during a 9-month trial work period, a 3-month adjustment period, and then for any months during a 36-month reentitlement period in which earnings fall below the SGA amount. The 3-month adjustment period begins whenever an individual has accumulated 9 months of trial work.

In the SSI program, a disabled recipient has his or her payment reduced $1 for each $2 in earnings beyond $65 a month. At the point where earnings reach the substantial gainful activity level, benefits are continued under certain circumstances under the 1619 program, named for the section of the Social Security that established it.

The increased earnings ceiling is expected to allow up to 71,000 individuals to retain or regain Social Security or SSI disability benefits.

(Taken from Social Security Information Items, July 1989)

Social Security Information Items, July 1989 and August 1989. Social Security Administration, Office of Information, Room 4-J-10 West High Rise, 6401 Security Boulevard, Baltimore, Maryland 21235.

FEDERAL PAYMENTS AND REDETERMINATION

In 1989, the maximum Federal SSI Payment is $368 a month for an eligible person and $553 a month for an eligible couple. Periodic redetermination for eligibility is required. The severity of the disability determines how often each case is reviewed. Recipients who are disabled and who are expected to have medical improvements will generally have their cases reviewed 6-18 months after payments begin. It is suggested that information and records be kept concerning income, resources, living arrangements and bank accounts because they may be needed for redetermination.

APPLICATION INFORMATION

When you go to the Social Security Office to apply for SSI for your child, take the following with you:

A. Medical Information

1. List of agencies from whom medical releases may be obtained to provide information about your child (schools, doctors, clinics, hospitals, etc.) Take with you the phone numbers and addresses of these agencies.

B. Income, Savings and Insurance Policy Information

1. W-2 statement of last year's income.
2. Savings and checking account numbers and records.
3. Stock and bond certificate numbers.
4. Any additional sources of income information (pensions, annuities, gifts, social security, welfare, etc.).
5. Insurance policies benefiting your child.
6. Insurance policies that have cash redeemable accounts.

C. Housing Information

1. Last year's tax notice on home, if owned, and last year's tax statement on additional land or property (boats, planes, property in other counties, etc.).
2. Lease and landlord's name, if renting.
3. Housing subsidy papers, if receiving subsidized housing.

D. Miscellaneous Information

1. Birth Certificates of all family members (original or certified copy of original).
2. Motor vehicle registrations.
3. Social Security cards (to insure correct number is given).
4. One or two month's household bills.
5. Burial fund records.
6. Name, address and phone number of your social worker.

If you do not have all of this information available, take what you do have with you. "...all of the information needed to complete your application does not have to be given when you apply. If this information is not available, you should file your application anyway. The Social Security workers must tell you what you need to complete the process. They must help you get any information they can." (The Elderly Legal Services Project, p.6), (Social Security Information Items, August 1989).

It may take up to three months for the Social Security Office to decide if your child is eligible for SSI. Ask the Social Security Worker about "presumptive disability funds"--money that they might be able to give you while they are looking over your records. If they finally decide that your child is not eligible for SSI, you do not have to pay back this money.

*If the child does not have a W-2 form or savings account, for example, the parents must submit their own records.

APPEALS

Recipients have the right to appeal any decision made about their eligibility or payment amount. There are four steps in the appeals process--reconsideration, hearing, Appeals Council review, and Federal court action--and there is a time limit for requesting each one. The individual who is handicapped or a court appointed guardian must sign the appeal form. Social Security offices will assist recipients in requesting an appeal.

Appeal Procedure Steps

1) Reconsideration

If you disagree with the denial of your application, you have the right to request that the evidence submitted and any additional evidence you may have, be evaluated by another person in the Agency. This is called a Reconsideration. You have 60 days from the date of receipt of the initial denial to file a Request for Reconsideration IN WRITING to your local Social Security Administration office.

2) Hearing

If you wish to challenge the denial further, you have a right to a hearing before an Administrative Law Judge. To get a hearing, you must file a WRITTEN request for a hearing within 60 days of receiving your Reconsideration denial.

At the hearing you will have an opportunity to explain to the Administrative Law Judge the reasons why you feel their decision is wrong. You may also describe the symptoms you experience and how your medical impairments prevent you from performing any of your former jobs.

You may bring witnesses to testify on your behalf, for example, your personal physician. You could bring your spouse, friends or relatives who know of your condition to testify for you. You may also present oral arguments explaining your circumstances and the reasons you feel that you are entitled to benefits.

Prior to the hearing, you should submit any additional medical records or doctor's letters that you have obtained since being denied.

You have the right to be represented by a lawyer, trained advocate or even an informed friend if you so desire.

3) Federal Court

It is possible that your case could be appealed all the way to the U.S. Supreme Court, though very few ever get that far. If you need more information about further appeals, talk to your local Social Security Administration office.

CHANGE OF STATUS

Changes that affect eligibility or payments must be reported to Social Security. Reporting of changes are to be made within 10 days following the month in which the changes were made. All recipients must report the following:

* Changes in their income, resources, household or living arrangements, or marital status.
* If they enter or leave an institution.
* If they leave the area of the U.S. and the Northern Mariana Islands.
* If they change their address.
* Married SSI recipients must report changes in their spouse's income and resources.
* If the SSI recipient is a child under 18 living with his or her parents, any change in the parents' income and resources must be reported.
* Disabled and blind recipients must let Social Security know if they take a job or become self-employed or if their condition improves.
* Students between 18 and 22 must report if they start or stop attending school.
* The income of ineligible children may affect their parents' SSI payment or an eligible child's payment.
* Changes in the income of eligible children who live in the household must be reported. Also, Social Security should be notified if an ineligible child living in the household reaches age 18 (or 21 if a student).

Reports can be made by phone or mail or in person at any Social Security office.

SAVE TIME AND TRAVEL

Social Security has added a new service whereby you can now conduct your Social Security business by phone toll-free. During regular business days (Monday - Friday), your call will be answered by an operator between 7:00 a.m. and 7:00 p.m. The toll-free number to call is **1-800-234-5772.**

FOR MORE INFORMATION

If you want more information about the SSI program, please contact any Social Security office. The people there will be glad to answer questions. The office phone number is listed in the local telephone directory under "Social Security Administration" or "U.S. Government". In Iowa, contact your local Social Security office or:

Social Security Administration
Des Moines District Office
Room 293 Federal Building
210 Walnut
Des Moines, IA 50309

(515) 284-4055

A monthly newsletter is also published and provides current changes and information on all Social Security programs including SSI. If you would like to receive the newsletter, contact the address below and ask to be placed on the mailing list to receive the Newsletter titled: **Social Security Information Items**.

Social Security Administration
Office Of Information
Room 4-J-10 West High Rise
6401 Security Boulevard
Baltimore, Maryland 21235

RESOURCES AND REFERENCES

Supplemental Income

A Guide to SSI for Groups and Organizations (1989, January). SSA Publication No. 05-11015, ICN 480300. (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309).

Benefits for Disabled People Who Return to Work (1987, July). (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309)

Doing Business with Social Security? USE Teleservice. (1986, September). (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309)

Discusses telephone service offered by the Social Security Administration.

SSI (1988, July). SSA Publication No. 05-11000, ICN 480200. Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309)

SSI Rules for Employment Set Aside (July/August 1988). DD Tips. (Bi-monthly publication of the Nebraska Developmental Disability Planning Council, Nebraska Department of Health, Lincoln).

Social Security Information Items, July 1989. Social Security Administration, Office of Information, Room 4-J-10 West High Rise, 6401 Security Boulevard, Baltimore, Maryland 21235.

Social Security Information Items, August 1989. Social Security Administration, Office of Information, Room 4-J-10 West High Rise, 6401 Security Boulevard, Baltimore, Maryland 21235.

State Supplementary Assistance. (Available from Bureau of Medical Services, Iowa Department of Human Services, Hoover State Office Building, Des Moines, Iowa 50319).

The State Supplementary Assistance Program in Iowa provides additional funds to persons who receive Supplemental Security Income (SSI), or who would be eligible for SSI benefits except that their income is too high.

The Elderly Legal Services Project. (1985). How to Apply For SSI. Available from Legal Services Corporation of Iowa, Des Moines, Iowa)

What You Have to Know About SSI. (1989, January). SSA Publication No. 05-11011, ICN 480265. (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309)

Your Social Security. (1987, January). (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309)

Overview of the Social Security system including: Application procedures, benefit schedule, eligibility, and the right of appeal.

Section Seven
TAX INFORMATION

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ANNUAL INCOME TAX GUIDE

The 1986 Tax Reform Act made major changes in the income tax laws. The most important change related to parenting a child with a disability was limiting the deductibility of medical and dental expenses. Taxpayers may now only deduct the part of medical and dental expenses and health insurance costs that exceed 7.5 percent of adjusted gross income.

Since many families that include a child with a disability have significant medical expenses that are not covered by health insurance or other reimbursement programs, this article will concentrate on medical expenses. The article will also discuss other aspects of current tax laws that are likely to affect our readers, including changed made during 1989 and special employment programs for adults with disabilities.

Let the IRS Know Who You Are

The IRS processes tax returns by a computer that automatically singles out any taxpayer who claims high deductions. Parents can reduce the likelihood of their tax returns being audited by explaining their child's disability and the deductions being claimed in a letter accompanying their return.

In addition, enclose a letter from the child's primary physician: (1) explaining the nature of the child's disability and the prescribed care, including a list of all specialists, therapists, physicians, and treatments necessary to the child's health and (2) verifying your child's participation in these programs. Be sure to keep copies of both letters for your files.

Keep Careful Records

It is of upmost importance to keep complete and accurate records! Record all expenses related to the child's disability - from expensive operations and prescribed drugs to over-the-counter medicine recommended by your physician. Always get a receipt to back up your records, whether you pay by check or in cash. If no formal receipt is available, note the specifics listed above on a slip of paper, have it signed, and file it with your records.

In a notebook record: (1) date of payment; (2) name and address of the person providing the service; (3) brief description of service provided; and (4) amount paid.

As a general practice, keep all cancelled checks, bills and receipts related to deductible expenses. Expenses are deductible in the year in which the payment is made. Thus, if a child has an operation in December, 1989, but the hospital bill is paid in January, 1990, the expense is deductible on your 1990 return.

Although it is not necessary to file all these records with a return, they will help you fill our your return correctly. Moreover, they are invaluable should the IRS audit your return. The IRS may audit tax returns up to seven years after they are filed - so keep all records in a safe place for seven years.

Medical Deductions

When a family's medical expenses exceed 7.5 percent of the family's adjusted gross income and parents are itemizing deductions on their tax return, all out-of-pocket expenses related to medical and dental care which were not reimbursed can be deducted. Remember that only the part of medical, dental expenses and health insurance costs which exceeds 7.5 percent of adjusted gross income is deductible. Taxpayers must be sure to reduce medical expenses by the total reimbursements received (including payments made directly to doctors or hospitals).

Medical expenses are payments made for diagnosis, treatment, or prevention of disease. Transportation costs to receive care are considered part of medical expenses as are health insurance payments.

Parents who pay medical expenses for a person who could have been claimed as a dependent except for the fact that the person had an income of $2,000 or more, or filed a joint return, can include such medical expenses as deductible on their tax return.

Changes For 1989

The major changes for parents this year are social security numbers for their children, reporting requirements with Child Care Credit, Employer Child Care Assistance, Earned Income Credit, Dependency Exemptions for Full-Time Students and Educational Savings Bonds.

Social Security Numbers. Beginning with 1989 tax returns, a social security number is required for children ages two and over. To obtain a social security number, file a Form SS-5 with your local Social Security Office. If a number is not received by the filing deadline, you can write "applied for" on the tax return.

Child Care Reporting Requirements. Working people who take tax credits or exclusions for dependent care and child and dependent care providers have new reporting requirements for income tax returns due April 1990.

A provisions of the Family Support Act of 1988 now requires that:

* care providers, except those that are tax-exempt, give their Taxpayer Identification Number (TIN) to any client who plans to take a credit or an exclusion for the cost of the care; and

* taxpayers who take this credit or exclusion must write in the correct name, address and TIN of the care provider on their federal income tax returns.

Generally, if you pay someone else to take care of your child who is under 13 or for a dependent with a disability, you may be able to take a tax credit of up to 30 percent of the cost of the care. Expenses for which the credit may be claimed are limited to $2,400 for one dependent and $4,800 for two or more. Employees whose employers provide child or dependent care may, under certain circumstances, exclude up to $5,000 of the value of this care from their gross income.

For individuals, their social security numbers are their correct TINS. For others, the employer identification number is usually the correct TIN. Care providers who willfully refuse to comply with this new requirement may be subject to a $50 penalty for each violation.

To claim this tax credit or take the exclusion for employer-provided assistance, get new IRS Form W-10, "Dependent Care Provider's Identification and Certification," and give one to each care provider to fill out and return. For example, if during the year you change from one provider to another, you would have to give a Form W-10 to both. This form, like the W-4 employees file with employers, does not go to the IRS. Instead, keep it with your records. Forms W-10 are available at an IRS office or may be ordered by calling 1-800-424-3676. You can write for forms as follows:

If you are located in Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, or Wyoming, send to: Forms Distribution Center, Rancho Cordova, CA 95743-0001.

If you are located in Alabama, Arkansas, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, North Dakota, Ohio, Oklahoma, South Dakota, Tennessee, Texas, or Wisconsin, send to: Forms Distribution Center, P.O. Box 9903, Bloomington, IL 61799.

If you are located in Connecticut, Delaware, District of Columbia, Florida, Georgia, Maine, Maryland, Massachusetts, New Hampshire, New Jersey, New York, North Carolina, Pennsylvania, Rhode Island, South Carolina, Vermont, Virginia, or West Virginia, send to: Form Distribution Center, P.O. Box 25866, Richmond, VA 23289.

In cases where a provider refuses to give all the necessary information, taxpayers should provide as much information as they can and keep records. A copy of a recently printed letterhead or billhead will serve to verify the provider's name and address. If the care provider is an employee, a copy of a properly prepared W-4, "Employee's Withholding Allowance Certificate", will have all the necessary information.

Employer Child Care Assistance. If an employer provided child care or so-called disabled dependent care services to allow a parent to work, the amount the employer paid within certain limits is not considered income to the parent. (The amount that can be excluded from income is limited to $5,000 for a joint return, $2,500 for a married person filing separately, or the amount of a parent's earned income if less than $2,500.) Such care must be provided under an employer's written plan that doesn't favor employees and meets other qualifications.

Some employers are assisting in the payment of dependent care (as well as medical care) by withholding a limited amount of funds from regular paychecks prior to calculating the usual income tax and social security deductions and then reimbursing employees for dependent care or medical costs (See Code Section 89). This enables the employee to pay these expenses with pre-tax dollars. Parents cannot receive child care credit if they receive this employer assistance.

For further information, contact the IRS at 1-800-424-3676 and ask for free IRS Publication 503, "Child and Dependent Care".

Earned Income Tax Credit. Taxpayers with an income under $19,340 and who have a child are eligible for an Earned Income Credit (EIC). If you are entitled to the EIC, you can subtract it from the tax you owe or get a refund even if you did not have tax withheld from your pay. The credit can be as much as $910.

To be eligible for EIC you must have earned income during the year. Generally, earned income includes wages, salaries, tips, and self-employment income. Earned income doesn't include social security payments, welfare benefits or unemployment compensation.

Certain conditions have to be met in order to take this credit. For example, you must have child living with you for more than half the year and your main home must be in the U.S. Your filing status must be married filing a joint return, qualifying widow(er) with dependent child, or head of household.

Because of higher minimum income for filing requirements, many families are no longer required to file a return. Even if you are not required to file an income tax return, if you qualify for the EIC you should file to get a refund. If you want, the IRS will figure both your tax and your EIC on From 1040 or 1040A. For further information, refer to the free IRS Publication 596, "Earned Income Credit".

Deduction for Dependents. If the taxpayer claims an individual as a dependent on his or her return, the dependent cannot claim a personal exemption on his or her own return.

For example, Mitch and Marion have a dependent child, Willard, who is blind. Willard is a full-time college student and works during the summer. Because Mitch and Marion can claim Willard as an exemption on their return, Willard cannot claim a personal exemption on his own return.

A taxpayer may claim an individual as a dependent if the individual meets all of the following requirements:

* The taxpayer provides at least half of an individual's support;

* The individual's gross income does not exceed $2,000, or he or she is under 19 years of age, or if he or she is over 19 and under 24 and is a full-time student. (Beginning in 1989 you may not claim a dependent exemption for a child who is 24 years old by the end of 1989 and had an income over $2,000, even though the child was a full-time student. Previously there was no age or income limit if the child was a full-time student. Taxpayers affected by this change may want to consider adjusting their withholding by filing a new Form W-4 with their employer).

* The individual lives in the taxpayer's household;

* The individual is a U.S. citizen during some part of the tax year in question;

* The individual does not file a joint income tax return on his or her own.

The amount of a dependent's standard deduction will differ depending on his or her income. The deduction allowed is the greater of $500 or the dependent's earned income.

For example, Willard is single and is claimed as a dependent on his parent's tax return. He has an earned income of $3,000 and is blind. His standard deduction is $3,000 because the greater of $500 or his earned income is $3,000. However, because he is blind, his standard deduction could be as much as $3,750, providing his income was equal to this amount. If his income was $5,000, his deduction would still be $3,850, the maximum allowable deduction for a single, 65 or older or blind individual.

Educational Savings Bonds. Beginning January 1, 1989 there is an exclusion from gross income for interest earned on U.S. Savings Bonds if proceeds from the bond are used by a taxpayer or his dependent to pay for tuition and required fees for attendance at an eligible educational institution, such as a two or four-year college or vocational school.

Employment Programs. Adults with disabilities receiving welfare or public assistance benefits can participate in certain programs under which special tax treatment occurs. When a person with a disability is paid by a state welfare agency for taking part in a work training program, he or she does not need to include the income in calculating gross income as long as the amount received does not exceed the welfare benefits that would have been received.

Under the Employment Opportunities for Handicapped Individuals Act, adults with disabilities can be employed in community service activities and need not include (in gross income) the wages, the allowances or the reimbursements (for attendant care, transportation, and other services that enable the person to work) paid to them under the act.

Individuals with disabilities who are employed can deduct expenses that are "impairment-related" such as attendant care or other services at the place of employment (paid for by the individual taxpayer) that enable the individual to work. To utilize this deduction requires filing Form 2106 and entering the amount calculated on that form onto the 1040 tax return form.

Business Tax Incentives. There are two tax incentives for businesses related to people with disabilities. First, a business may deduct up to $35,000 of the cost of removing architectural or transportation barriers. Second, tax credits are available for hiring a so-called targeted group including certain people with disabilities, such as those referred by vocational rehabilitation programs and Supplemental Security Income (SSI) recipients. For more information on targeted jobs credit, see Publication 572, "General Business Credit".

Additional information about tax credits and deductions can be obtained by calling the District Internal Revenue Services offices at 1-800-424-1040. Also, the IRS issues a number of free publications relevant to persons with disabilities:

* #17; Your Federal Income Tax
* #502: Medical and Dental Expenses
* #503: Child and Dependent Care
* #526: Income Tax Deductions for Contributions
* #907: Tax Information for Handicapped and Disabled Individuals
* #933: Major Tax Law Changes Enacted in 1988.

To order these publications call, 1-800-424-FORM.

-C.K.-

This article was prepared with the help of Maritza Melecio, Assistant Public Affairs Officer of the Internal Revenue Service, Boston Office.

Note: From Exceptional Parent (pp. 30-34), November/December 1989, Boston, MA: Exceptional Parent Magazine, Copyright 1989. Reprinted with permission of Exceptional Parent, 1170 Commonwealth Ave., Boston, MA 02134.

ITEMIZED MEDICAL DEDUCTIONS

* Extra costs for salt-free or other special food; prescribed by a doctor
* A stereo for a person confined to the house
* Hand controls for the car of a person with disabilities
* A car telephone for a person who may require immediate medical assistance
* Lip-reading instructions
* Extra costs for medically necessary equipment, such as a whirlpool, central air conditioning, or swimming pool
* Health insurance premiums
* Fees to doctors, dentists, hospitals, clinics
* Fees for x-rays and tests
* Fees for in-patient treatment or rehabilitation services
* Fees for physical therapy, occupational therapy, and speech therapy, or any medically-prescribed therapy
* Payments for prescriptions and medical supplies (be sure to have a doctor's written recommendation for supplies)
* All long-distance phone calls related to medical care, scheduling of medical appointments and ordering medical supplies
* Out-of-pocket expenses for prescribed medical equipment, including wheelchair, crutches, braces, special mattresses, boards and the cost to maintain them (again, a written prescription is needed)
* Ambulance services
* Mileage or transportation costs to get medical care, pharmacy or medical supplies
* Expenses for gas, tolls, and parking of an automobile to and from the hospital, clinic or pharmacy
* Meal and hotel costs related to getting medical care for any family member and the cost of a parent's lodging, meals and transportation if a parent needs to accompany a child to receive health services
* Cost of eye glasses, contact lenses, and hearing aids, including eye and hearing examination fees
* Tuition or fees for tutoring that is prescribed by your physician

* The cost of special schools or camps designed to treat a disability, including the cost of meals and lodging, when prescribed by a physician

* The cost to parents for attending a special workshop concerning their child's disability, or anything related including subscriptions to disability publications, such as EXCEPTIONAL PARENT, if prescribed by a physician

* Capital expenses (amounts paid for special equipment installed in your home, such as a wheelchair, or for improvements if the main reason is for medical care). Note: The amount deductible is the cost less any increase in value of your home.

* Personal use items ordinarily used for personal, living, and family purposes if it is used primarily to prevent or alleviate a disease or disability

* Cassette books for a person with a vision impairment may be included (if prescribed). The difference in cost between the special cassette and the ordinary cost of the book is considered a medical expense

* Television: the cost of equipment that displays the audio part of television programs as subtitles for people with hearing impairments. This may include the cost of an adapter that attaches to a regular set.

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Order Form

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EXCEPTIONAL PARENT has served parents and professionals concerned with the care of children and adults with disabilities since 1971. Yearly subscriptions (8 issues) are available for $18 for individuals and $24 for organizations, schools, and libraries. Canadian and foreign subscribers please add $5 per year extra postage. Payment in US $ only.

Name_____

Address_____

City_____

State_____ Zip_____

Mail to: EXCEPTIONAL PARENT
P.O. Box 3000, Dept EP
Denville, New Jersey 07834

Section Eight
ADDITIONAL INFORMATION

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SOURCES OF FREE HELP IN IOWA

Alliance for the Mentally Ill
Box 495
Johnston, IA 50131
515-225-8666
Director/Administrator: Margaret Stout

Eligibility: Any consumer of mental health services in Iowa.

Services: Advocacy (in areas of employment, community living, education, habilitation/rehabilitation, and treatment); information and referral; public education; assistance in organizing self-help groups for the mentally ill.

Iowa Civil Liberties Union
516 Shops Building
Des Moines, IA 50309

Director/Administrator: Cryss Farley

Eligibility: Any individual who feels a law or regulation unconstitutionally deprives him/her of rights.

Services: Advocacy; public education; legal assistance; legislative assistance.

Iowa Department of Human Rights
Lucas State Office Building
Des Moines, IA 50319
515-281-5960 or 1-800-532-1465

Director/Administrator: Gretchen Hamlett

Eligibility: Any Iowan who feels that he/she is the victim of discrimination (age, sex, race, national origin, color, creed or disability).

Services: Investigation of and adjudication of complaints alleging unfair or discriminatory practices; public education; legislative assistance, public policy advocacy.

Iowa Protection & Advocacy Services, Inc.
3015 Merle Hay Road, Suite 6
Des Moines, IA 50310
515-278-2502

Director/Administrator: Mervin Roth

Eligibility: Any developmentally disabled or mentally ill citizen of Iowa.

Services: Protection and advocacy; legal assistance.

Legal Services Corporation of Iowa
315 E. 5th Street
Des Moines, IA 50309
515-243-2151 or 1-800-532-1275

Director/Administrator: Randi Youells

Eligibility: Low-income Iowans.

Services: Legal Assistance; public education.

Mental Health Association of Iowa
P.O. Box 8283
Des Moines, IA 50301
515-255-4174

Contact Person: Darlene M. Brown

Eligibility: Any mentally ill citizen of Iowa.

Services: Information/referral; advocacy (in areas of employment, community living, education, rehabilitation and treatment); public and professional education; legislative services.

Office of the Ombudsman
State of Iowa
(also known as Iowa Citizens Aide Office)
State Capitol
Des Moines, IA 50319
515-281-3592

Director/Administrator: William P. Angrick II

Eligibility: Open to all residents of Iowa, including those confined to institutions who have complaints against agencies of Iowa government.

Services: Advocacy; investigation of complaints against state and local government.

From: Poor People's Press. Des Moines, IA: Legal Services Corporation of Iowa. 14-15.

MORE SOURCES OF FREE (OR LOW COST) HELP IN IOWA

Iowa Department of Education
Bureau of Special Education
Grimes State Office Building
Des Moines, IA 50319
515-281-3176

Iowa Department of Education
Division of Vocational Rehabilitation Services
510 E. 12th St.
Des Moines, IA 50319
515-281-4311
Outside Des Moines: 1-800-532-1486

Iowa Department of Human Services
Hoover State Office Building
Des Moines, IA 50319
515-281-3147

Social Security Administration
U.D. Department of Health and Human Services
Room 293 Federal Building
210 Walnut Street
Des Moines, IA 50309
1-800-532-1440

TRANSITION COORDINATORS

IOWA AREA EDUCATION AGENCIES

Each Area Education Agency has identified an individual to assist local school districts, professionals, parents, etc. as students with disabilities move from school to adult life. These individuals are an excellent source of information as parents and educators develop and implement plans for the future of young adults with disabilities.

Transition Coordinators for the 1989-1990 school year are:

Janice SyWassink, Keystone AEA 1
New Hampton Field Office
R.R.#1, 1000 West Hamilton
New Hampton, IA 50659
515-394-2162

(VACANT), Northern Trails AEA 2
P.O. Box M
Clear Lake, IA 50428
515-357-6125

Diane Nelson, Lakeland AEA 3
Box 38
Cylinder, IA 50528
712-424-3720

D. L. Steen, AEA 4
102 South Main Ave.
Sioux Center, IA 51250
712-722-4374

Harley Harlan, Arrowhead AEA 5
1235 5th Avenue South
Fort Dodge, IA 50501
515-576-7434

Linda Lewis, AEA 6
210 South 12th Ave.
Marshalltown, IA 50158
515-752-1578

Sue Gronewold, AEA 7
3706 Cedar Heights Drive
Cedar Falls, IA 50613
319-273-8250

Jane Rock, Mississippi Bend AEA 9
729 21st St.
Bettendorf, IA 52722
319-359-1371

Lucy Choisser, Grant Wood AEA 10
Coralville Office
200 Holiday Road
Coralville, IA 52241
319-351-2510

Ed O'Leary, Heartland AEA 11
Newton Office
301 First St. S.
Newton, IA 50208
515-792-4870

Medha Johnson, Western Hills AEA 12
1520 Morningside Avenue
Sioux City, IA 51106
712-274-6010

Deborah Taylor, Loess Hills AEA 13
Halverson Center for Education
P.O. Box 1109
Council Bluffs, IA 51502
712-366-0503

Al Mackdanz, Green Valley AEA 14
Green Valley Road
Creston, IA 50801
515-782-8443

Al Hodgeman, Southern Prairie AEA 15
Route 5, Box 55
Ottumwa, IA 52501
515-682-8591

John Youngquist, Great River AEA 16
1200 University
Burlington, IA 52601
319-753-6561

(VACANT), Des Moines Public Schools
1800 Grand Avenue
Des Moines, IA 50307
515-242-7714

RESOURCES AND REFERENCES

Resources and References

A Brief Explanation of Medicare, (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293, Federal Building, 210 Walnut Street, Des Moines, Iowa 50309).

A Guide To Guardianships and Conservatorships (1988). Iowa Protection & Advocacy Services, Inc., 3015 Merle Hay Road, Suite 6, Des Moines, IA 50310.

A Guide to Health Care Coverage for the Child with a Chronic Illness or Disability. (Available from Center for Public Representation, 520 University Ave., Madison, Wisconsin 53703).

> This guide is another source on insurance issues. The guide was prepared by Alice Leonard for the Community Based Maternal and Child Health Project of the Center for Public Representation in Madison, Wisconsin. Although the resources are for Wisconsin residents, most of the information is relevant for other states. Cost is $10.00

A Guide to SSI for Groups and Organizations (1989, January). SSA Publication No. 05-11015, ICN 480300. (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309).

Ann Hart Wernz, Esq. (1984). Planning for the Disabled Child. (Available from The Northwestern Mutual Life Insurance Company, 212 Insurance Exchange Building, Des Moines, Iowa 50309)

> Provides an outline of the problems requiring special attention for parents making plans for adults or children with disabilities. Also offers suggestions for personal care and financial assistance of the individual with a disability after the parents' deaths. This pamphlet is one of the resources that deals with insurance as part of the available estate planning tools for disabled children.

ARC National Insurance and Benefits Committee (1984). How to Provide for their Future. Arlington, TX: Association for Retarded Citizens.

> The authors have tried to show the interrelationship between the child's prospective needs for social and/or economic supports, as individually assessed, and the formal mechanisms which can be brought to bear on them--insurance, trust provisions, governmental benefits for the disabled and guardianship. The chapters are: Guardianship, Wills, Trusts and General Estate Planning, Insurance Benefits, and Governmental Benefits.
> Cost: $3.00.

Association for Retarded Citizens of the United States Group Term Life Insurance Plan. (Available from Association for Retarded Citizens, Group Insurance Administrator, Association Consultants, Inc., 600 W. Fulton Street, Chicago, IL 60606.)

> Fact sheet highlighting the benefits and coverages of the group policy issued to the Association for Retarded Citizens of the United States through American Heritage Life Insurance Company.

Benefits for Disabled People Who Return to Work (1987, July). (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309)

Beyer, H.A. (December, 1986). Estate Planning: Providing for Your Child's Future (December, 1986). The Exceptional Parent, pp. 12-15.

Camp Courageous of Iowa - Respite Care. For more information contact Charlie Becker, Executive Director, Camp Courageous of Iowa, R.R. #2, P.O. Box 455, Monticello, IA 52310-0455.

Camp Sunnyside. For more information contact Pete Theismann, Director of Camping and Recreation, Camp Sunnyside, P.O. Box 4002, Des Moines, IA 50333.

Center for Law and Health Sciences. (1986). Estate Planning for Parents of Persons with Developmental Disabilities. (Available from Disability Law Center, Inc., 11 Beacon Street, Suite 925, Boston, MA 02108).

> This booklet is written to assist parents of disabled persons in planning their estates. Topics covered include: Inheritance, Life Insurance, Property, Trusts, Guardianship, Conservatorship, Representative Payee and Banking Arrangements. An appendix is included that describes Government Benefits and Services such as SSI, Medicaid, Social Security, Veterans Benefits and Vocational Rehabilitation.

Community Living Foundation for Iowans With Developmental Disabilities. For more information contact Chris Morton, Community Living Foundation, 2402 Forest Avenue, Des Moines, IA 50311.

Doing Business with Social Security? USE Teleservice. (1986, September). (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309)

> Discusses telephone service offered by the Social Security Administration.

Early and Periodic Screening, Diagnosis and Treatment (EPSDT). For more information contact Joe Mahrenholz, Supervisor, Non-Institutional Services and Utilization Review Section, Bureau of Medical Services, Iowa Department of Human Services, Hoover State Office Building, Des Moines, IA 50319.

Estate Planning for the Disabled. P.O. Box 808, Manteca, CA 96336-0808, (209) 239-7558 or (916) 928-1400.

> EPD is a nonprofit corporation, the purpose of which is to counsel and assist parents of special needs children to develop (at the lowest possible cost) viable estate plans, letters of intent, wills and special needs trusts. Estate teams consisting of a planner, attorney, and a CPA have been organized in several California locations and elsewhere in the country. Special payment plans and discounts are available to low-income families. Seminars, workshops and resource lists are among the services offered. Callers from other states will be assisted or referred to appropriately trained and experienced attorneys and financial specialists.

Family Support Subsidy Program. For more information contact Division of MH/MR/DD, Department of Human Services, Hoover State Office Building, Des Moines, IA 50319.

Fruge, D.L. & Green, K.O. (1982). Estate Planning for Retarded Persons and Their Families. Atlanta, GA: Mississippi Department of Mental Health.

Goldberg, I.V. & Frank, A.L. (1989). Estate Planning to Meet the Special Needs of a Severely Disabled Child. Estate Planning, pp. 232-236.

Hager, Dr. William, Commissioner of Insurance for the State of Iowa, Iowa Insurance Division, Lucas Building, Des Moines, IA 50319. General Information: (515) 281-5705 Complaints/Inquiries: (515) 281-4241

> Contact the Commissioner of Insurance for the State of Iowa if you have an existing insurance policy for an individual with a disability and are having a problem with its administration or think that the policy is being mishandled. The Commissioner of Insurance can also be contacted to find out the financial condition of an insurance company or HMO.

Iowa Association for Retarded Citizens. For more information contact Mary Etta Lane or Esther Fields, ARC/Iowa, 715 East Locust, Des Moines, IA 50309.

Iowa Association of Rehabilitation and Residential Facilities, Iowa Facilities Management Information System Program Definitions. Michael Crawford, Iowa Association of Rehabilitation and Residential Facilities, 913 9th St., Suite 3, West Des Moines, Iowa 50265.

Iowa Child and Adolescent Service System Program (CASSP). For more information contact Iowa Child and Adolescent Service System Program, Division of MH/MR/DD, Iowa Department of Human Services, 5th Floor, Hoover Building, Des Moines, IA 50319.

Iowa Comprehensive Health Association, State Comprehensive Health Association. (Available from Administrator: Mutual of Omaha Insurance Company, P.O. Box 31746, Omaha, NE 68131 or phone 1-800-445-8603).

> This brochure describes the benefits, exclusions, eligibility and application procedures for the ICHA Program.

Iowa Directory of Services for Persons With Developmental Disabilities. Available from the Iowa University Affiliated Facility, Division of Developmental Disabilities, University of Iowa Hospital School, University of Iowa, Iowa City, IA 52242

> Every two years, the Governor's Planning Council for Developmental Disabilities and the Iowa University Affiliated Facility publish a directory of services to assist in locating appropriate resources to provide for the needs of the developmentally disabled.

McManus, M.A. (1988). Understanding Your Health Insurance Options: A Guide for Families Who Have Children With Special Health Care Needs. Association for the Care of Children's Health, 3615 Wisconsin Ave., Washington, D.C.

> Explanation and comparison of private insurance, HMOs and PPOs. Worksheets and case study examples are provided to assist families in comparing and determining the best health care coverage that takes into account enrollment, cost and benefits factors. (Cost: $2.75 plus $1.00 shipping and handling per copy).

Medicaid and You, (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293, Federal Building, 210 Walnut Street, Des Moines, IA 50309).

Medicaid for Iowa ADC Recipients and ADC-Related Recipients, rev. (1989, July). (Available from Iowa Department of Human Services, local county offices).

> Highlights eligibility, program requirements, services available, application and payment procedures, and your responsibilities as a recipient of Medicaid in the ADC and ADC-related programs.

Medicaid for SSI Related Persons, rev. (1989, April). (Available from Iowa Department of Human Services, local county offices).

> Highlights eligibility, program requirements, services available, application and payment procedures, and your responsibilities as a recipient of Medicaid in the SSI related programs.

Medicaid for the Medically Needy, (1989, October). (Available from Iowa Department of Human Services, local county offices).

> Discusses eligibility, program requirements and procedures, and medical services available for the medically needy through the Medicaid program.

Medicaid Made Easy. (Purchase or order through your local bookstore or order directly from Addison-Wesley Publishers, 1-800-447-2226, Cost $10.95).

> Medicaid Made Easy is a guide that explains what Medicare does and does not cover, hospital discharge rights and how to negotiate doctor's fees, plus much more. The guide has an easy to understand approach on how to wade through the regulations surrounding Medicare.

Muscular Dystrophy Association. For more information contact Muscular Dystrophy Association, 1000 73rd Street, Suite 15, Des Moines, IA 50311.

National Maternal and Child Health Resource Center, (1989). College of Law Building, The University of Iowa, Melrose and Byington Streets, Iowa City, IA 52242.

> Julie Beckett, Associate Director of Consumer Affairs, National Maternal and Child Health Resource Center, is willing to answer questions parents and others may have concerning health care financing for the disabled. Contact her at the above address.

NEW HATS, INC., P.O. Box 57567, Salt Lake City, Utah, (801) 259-6613.

O'Leary, E.E. & Trotter, S.K., Transition Planning: Resource Directory of Services for Special Needs Populations, (Fall, 1989).

> The fourth edition of the Transition Planning: Resource Directory of Services for Special Needs Populations is a compilation of information and services obtained from agencies, organizations, and institutions throughout Area 11. The Directory is intended to be used as a reference for transition services and/or support identification. This publication is available through Heartland Area Education Agency 11, Newton Branch Office, 301 First St. S., Newton, IA 50208.

Parental Self Assessment: Assuring Future Care of Disabled Dependents. (1987, Summer) WAYS, pp. 6-11.

Provides parents with planning checklists that deal with necessary future planning documents (Will, Trust, Letters of Direction) and services (adult daily living, health care, vocational/day training, financial management, general advocacy services, residential services and others).

Russell, L.M. (1976). Alternatives: A Family Guide to Legal and Financial Planning for the Disabled. Evanston, IL: First Publications.

As an attorney with a mentally handicapped brother, the author addresses such questions as: Does my child need a legal guardian? Am I taking advantage of all the possible medical deductions and credits I am entitled to receive? What is the easiest way of obtaining medical insurance for my handicapped child? Chapter titles are: Wills, Guardianship, Trusts, Government Benefits, Taxes, Insurance and Financial Planning. $11.95. (Gives questions, not answers).

SSI (1988, July). SSA Publication No. 05-11000, ICN 480200. Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309)

SSI Rules for Employment Set Aside (July/August 1988). DD Tips. (Bi-monthly publication of the Nebraska Developmental Disability Planning Council, Nebraska Department of Health, Lincoln).

Social Security Information Items, July 1989. Social Security Administration, Office of Information, Room 4-J-10 West High Rise, 6401 Security Boulevard, Baltimore, Maryland 21235.

Social Security Information Items, August 1989. Social Security Administration, Office of Information, Room 4-J-10 West High Rise, 6401 Security Boulevard, Baltimore, Maryland 21235.

State Supplementary Assistance. (Available from Bureau of Medical Services, Iowa Department of Human Services, Hoover State Office Building, Des Moines, Iowa 50319).

The State Supplementary Assistance Program in Iowa provides additional funds to persons who receive Supplemental Security Income (SSI), or who would be eligible for SSI benefits except that their income is too high.

Sunnyside Adventure Camp. For more information contact Pete Theismann, Director of Camping and Recreation, Camp Sunnyside, P.O. Box 4002, Des Moines, IA 50333.

Sunnyside Respite Services. For more information contact Jack Denniston, Recreation Director, Easter Society of Iowa, Inc., P.O. Box 4002, Des Moines, IA 50333.

The Elderly Legal Services Project. (1985). How to Apply For SSI. Available from Legal Services Corporation of Iowa, Des Moines, Iowa)

There's No Place Like Home [Film]. Produced by the Iowa University Affiliated Program. Available from The Clearinghouse at the Division of Developmental Disabilities, University Hospital School, Iowa City, IA 52242, 1-800-272-7713.

Turnbull, H.R., Turnbull, A.P., Bronicki, G.J., Summers, Jean Ann, & Roeder-Gordon, C. (1989). Disability and the Family: A Guide to Decisions for Adulthood. Baltimore: Paul H. Brookes.

What You Have to Know About SSI. (1989, January). SSA Publication No. 05-11011, ICN 480265. (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309)

Your Guide to Medicaid, rev. (1988, November). (Available from Iowa Department of Human Services, local county offices).

A guide to the types of services and supplies available through Medicaid.

Your Social Security. (1987, January). (Available from U.S. Department of Health and Human Services, Social Security Administration, Room 293 Federal Building, 210 Walnut Street, Des Moines, Iowa 50309)

Overview of the Social Security system including: Application procedures, benefit schedule, eligibility, and the right of appeal.